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International Protection of Children's Right to Health: The Medical Screening of Newborns

Sanford J. Fox

Diony Young

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INTERNATIONAL PROTECTION OF CHILDREN'S RIGHT TO HEALTH: THE MEDICAL SCREENING OF NEWBORNS†

SANFORD J. FOX* and DIONY YOUNG**

I. INTRODUCTION	1
II. THE MEDICAL AND EPIDEMIOLOGICAL CONTEXTS OF NEWBORN SCREENING	4
III. THE MEANING OF "HEALTH".....	11
IV. THE EVOLUTION OF ARTICLE 24.....	13
A. <i>The World Health Organization</i>	13
B. <i>The Universal Declaration of Human Rights</i>	18
C. <i>The Declaration on the Rights of the Child</i>	19
D. <i>The International Covenant on Economic, Social and Cultural Rights</i>	20
V. NEWBORN SCREENING AND THE RIGHT TO HEALTH UNDER ARTICLE 24 OF THE CONVENTION	31
A. <i>The Contingent Nature of Health Rights Under the Convention</i>	31
B. <i>Monitoring Implementation Under the Convention</i>	35
VI. CONCLUSIONS.....	42

I. INTRODUCTION

This paper deals with two relatively unfamiliar ideas—that children have legal rights and that both health and the provision of health care are subjects of international law. Although children's rights in some form are not a new phenomenon, one of the most prominent and novel features of contemporary children's rights is their appearance in international law as part of the widespread movement to promote human rights.¹ This paper is concerned with

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* Professor of Law, Boston College Law School.

** Editor, *BIRTH: ISSUES IN PERINATAL CARE AND EDUCATION*; and Consultant in Maternal and Child Health, Geneseo, New York.

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¹ The provision of a right to health in international human rights law opens the possibility of achieving protection of health rights for Americans despite assertions by American courts that the federal Constitution requires neither the states nor the federal government to assure health care. See Curran, *The Constitutional Right to Health Care: Denial in the Court*, *NEW ENG. J. MED.*, Mar. 23, 1989 at 788. It seems, therefore, inappropriate to conclude that in the face of these denials "the only other constitutional or legal remedy remaining would be to amend the Constitution formally to establish such a new civil right." *Id.* at 789.

one particular international human right of children, namely their right to health.

The discussion of this children's right to health encompasses a range of related questions such as the meaning of "health" in this context, the evolution of the international right to health, and the nature of the legal obligation to protect children's right to health that is imposed on governments by international law. The central focus, however, is on how the international right to health becomes translated from legal doctrine to health care reality for children. Thus, the concern is not with the particular health benefits that are provided for children, but rather with the question of when and how that provision of benefits is required by the rules and processes of the international legal order. This question is examined using the medical screening of newborns² as the framework of analysis for a number of reasons: (1) screening has come to be a widespread health practice in many parts of the world; (2) a commonly held international health goal—the prevention of infant mortality and morbidity—can be significantly advanced by screening; and (3) an examination of screening raises the question of how to assure equal rights for all children in a very unequal international community.³

The most relevant international law involved in this inquiry appears in the latest multilateral human rights treaty, one that is comprehensively concerned with children, including their right to health. The Convention on the Rights of the Child (Convention)⁴

² "Medical screening of newborns" refers to a medical procedure involving the testing of neonates—children under the age of 28 days—for evidence of the presence of certain disorders, followed by treatment designed to prevent or control the clinical manifestations of these disorders. This is elaborated in Part II, *infra* p. 00.

³ It has been noted that "the acquisition and development of new techniques of medical care give rise to a new inequality in so far as the advantages resulting from these realizations—even in highly developed countries—remain reserved to a few privileged persons." HAGUE ACADEMY OF INTERNATIONAL LAW, *THE RIGHT TO HEALTH AS A HUMAN RIGHT* 145 (R. Dupuy ed. 1979) (comments by M. Séduilh at The Hague on July 27–29, 1978). The 1988 program review by UNICEF projects further inequalities:

According to UN/DIESA (Department of International Economic and Social Affairs) projections for the year 2000, the new century will dawn with an average annual per capita income of US\$13,666 in the wealthiest nations and an average annual return of US\$217 for people in the least developed African countries—US\$12 a year less than in 1985. According to DIESA's mid-year estimates, more than one billion people in the year 2000 will earn less than US\$300 a year.

UNICEF, 1989 ANNUAL REPORT 5 (1989).

⁴ *Convention on the Rights of the Child*, G.A. Res. 44/25, U.N. Doc. A/RES/44/25 (1989), reprinted in 28 I.L.M. 1448, 1456–76 (1989), with an addendum in 29 I.L.M. 1340 [hereinafter *Convention*].

Article 1 of the Convention defines "child" as "every human being below the age of

came into force on September 2, 1990.⁵ It contains a relatively detailed description of the right to health. Article 24 of the Convention provides:

1. States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.

2. States Parties shall pursue full implementation of this right and, in particular, shall take appropriate measures:

(a) To diminish infant and child mortality;

(b) To ensure the provision of necessary medical assistance and health care to all children with emphasis on the development of primary health care;

(c) To combat disease and malnutrition, including within the framework of primary health care, through, *inter alia*, the application of readily available technology and through the provision of adequate nutritious foods and clean drinking-water, taking into consideration the dangers and risks of environmental pollution;

(d) To ensure appropriate pre-natal and post-natal health care for mothers;

(e) To ensure that all segments of society, in particular parents and children, are informed, have access to education and are supported in the use of basic knowledge of child health and nutrition, the advantages of breast-feeding, hygiene and environmental sanitation and the prevention of accidents;

(f) To develop preventive health care, guidance for parents and family planning education and services.

3. States Parties shall take all effective and appropriate measures with a view to abolishing traditional practices prejudicial to the health of children.⁶

4. States Parties undertake to promote and encourage international cooperation with a view to achieving progressively the full realization of the right recognized in this article. In this regard, particular account shall be taken of the needs of developing countries.⁷

As a necessary prelude to examining whether medical screening is embraced by Article 24 and, if it is, how it might be enforced, it is necessary first to provide some of the scientific background and then outline the doctrinal evolution of Article 24.

eighteen years unless, under the law applicable to the child, majority is attained earlier." *Id.* at art. 1.

⁵ 29 I.L.M. 1339 (1990).

⁶ This paragraph is designed primarily to eradicate female circumcision.

⁷ *Convention, supra* note 4, at art. 24.

II. THE MEDICAL AND EPIDEMIOLOGICAL CONTEXTS OF NEWBORN SCREENING

Few health issues have occupied the world community as intensely as the prevention of infant mortality.⁸ The prevention of disease generally has been a long-standing public health and social goal, but the technical tools for identifying the serious inherited and treatable metabolic disorders in the first days of life did not appear until the 1950s. Most noteworthy was the detection in newborn infants of phenylketonuria (PKU),⁹ discussed below. It is estimated that currently available tests can screen for approximately fifty medical disorders.¹⁰ However, in the United States, generally the maximum number of disorders for which newborn screening programs are covered in any state's medical detection system is seven.¹¹

A recent report on international newborn screening indicates that in most countries no screening is done. In thirty jurisdictions—including the United States—there is screening for PKU and congenital hypothyroidism,¹² and in sixteen of those countries the

⁸ UNICEF counts as its central measure of international achievement the movement in the mortality rate for children under 5 years of age (U5MR), computed as the number of such deaths per 1,000 live births in each country. See UNICEF, *supra* note 3, at 28. In 1988, the worldwide U5MR ranged from 304 (Afghanistan) to 7 (Finland and Sweden) with nearly one half of the world (49%) reporting more than 95 and only 10 countries (7%) reporting a rate of 10 or less. *Id.* at 28–29.

⁹ See Naylor, *Recent Developments in Neonatal Screening*, 9 SEMINARS IN PERINATOLOGY 232 (1985).

¹⁰ J. TUERCK, R.M. BUIST, G. HIGGINSON, & M. SKEELS, *THE NORTHWEST REGIONAL NEWBORN SCREENING PROGRAM: PRACTITIONER'S MANUAL 1* (4th ed. 1988) [hereinafter J. TUERCK].

¹¹ *National Screening Status Report*, 13 INFANT SCREENING NEWSL. 11 (1990). Variation in the screening programs in this respect is illustrated by the regional screening done in Oregon, Montana, Nevada, and Alaska. These states screen for PKU and six of the seven other disorders to be discussed in the immediately following text, omitting the sickle cell test. The program in Alaska, however, also includes congenital adrenal hyperplasia, which produces shock, dehydration, and virilization of females. This occurs in Eskimo populations at a rate of 1:282. J. TUERCK, *supra* note 10, at 2.

¹² *International Screening Status Report*, 11 INFANT SCREENING NEWSL. 26–27 (1988). See description of congenital hypothyroidism *infra* p. 8. The thirty jurisdictions are: Australia, Australian External Territories, Austria, Belgium, Brazil, Canada, Costa Rica, Czechoslovakia, Denmark, France, German Democratic Republic (now part of the Federal Republic of Germany), Federal Republic of Germany, Greece, Iceland, Ireland, Israel, Japan, Mexico, Netherlands, New Zealand, Norway, Poland, Portugal, Sweden, Switzerland, U.S.S.R., United Kingdom, United States, the Vatican, and Yugoslavia. Finland screens for congenital hypothyroidism but not for PKU. *Id.*

screening program includes other disorders as well.¹³ The report indicates that three Latin American countries constitute the only developing nations that engage in routine screening,¹⁴ despite the importance of this mechanism to detect some hemoglobinopathies in much of Africa and Southeast Asia.¹⁵ The most common disorders, for which newborn screening is performed in the United States, are the following:

1. *Phenylketonuria* is a disease caused by the genetic deficiency of a liver enzyme that produces severe mental retardation, seizures, and psychotic behavior¹⁶ unless treatment is begun shortly after

¹³ *Id.* The "other" category is reported for Australia, Australian External Territories, Austria, Belgium, Costa Rica, German Democratic Republic (now part of the Federal Republic of Germany), Federal Republic of Germany, Greece, Ireland, Israel, Japan, Mexico, New Zealand, Poland, Sweden, and Switzerland. *Id.*

¹⁴ Brazil, Costa Rica, and Mexico all conduct routine screening. *Id.*

¹⁵ See Stein, Berg, Jones, & Detter, *A Screening Protocol for a Prenatal Population at Risk for Inherited Hemoglobin Disorders: Results of Its Application to a Group of Southeast Asians and Blacks*, 150 AM. J. OBSTETRICS & GYNECOLOGY 333 (1984). The report by Cameroon under the International Covenant on Economic, Social and Cultural Rights remarks that, "[b]roadly speaking, the health situation remains characterized by high morbidity and mortality rates resulting from transmissible diseases . . . as well as . . . haemoglobinopathies . . ." *Implementation of the International Covenant on Economic, Social and Cultural Rights; Initial Reports Submitted by States Parties to the Covenant, in Accordance with Council Resolution 1988 (LX), Concerning Rights Covered by Articles 10-12: Cameroon*, at 14, U.N. Doc. E/1986/3/Add.8 (1987). This procedure is not financially burdensome comparatively. "Newborn screening for hemoglobinopathies in populations at risk is accurate, rapid, and relatively inexpensive when compared to screening for PKU, hypothyroidism, and other metabolic disorders." Law, Craven, & Sarafidis, *Screening of Newborns for Hemoglobinopathies: Results in 5,484 Patients*, 57 DEL. MED. J. 161, 163 (1985).

¹⁶ Naylor, *supra* note 9. Domestic judicial remedies, as well as international law, may be implicated in the requirement to engage in screening. In the United States, for example, a negligent failure to diagnose PKU can lead to substantial damages from a jury in a malpractice action. See, e.g., *Marcel v. Louisiana Dep't of Pub. Health*, 492 So. 2d 103 (La. Ct. App. 1986), upholding an award of \$1.3 million on the basis of the trial court's finding that plaintiff Dena's

chances for a normal life have been obliterated, and she is condemned to live on a sub-human level.

Unrecognized and untreated PKU has resulted in such pronounced retardation that Dena's IQ is only 48. Her intellectual development is close to its maximum. No significant improvement in her intellectual development is likely . . . Her low IQ will prevent Dena from ever progressing beyond special education. She will never be self-sufficient enough to live alone. If she can ever find employment, it will only be token employment for the severely handicapped . . . She will never understand money.

. . . Dena experiences epileptic seizures. Dena is subject to behavioral problems and psychiatric and psychological disorders . . .

PKU makes Dena hyperactive and irritable. PKU has shortened her attention span

birth.¹⁷ By the early 1960s, laws began to appear in the United States that required PKU testing of all neonates, and today it is done in every state and in twenty-nine other countries.¹⁸ The treatment normally consists of strict observance of a diet low in phenylalanine for at least the first six years,¹⁹ although there are variant forms of the disease that require more complex treatment. It is estimated that PKU generally afflicts 1 in 15,000 newborns in the United States, although the prevalence is reported to vary among ethnic groups from 1 in 6,000 to less than 1 in 25,000;²⁰ the worldwide frequency is reported to be 1 in 10,000.²¹ Thus, of the more than 122 million children born in the Third World in 1987, approximately 12,220 of them suffered from PKU,²² although it could be as high as 20,000 (applying the 1:6,000 rate). On the other hand, studies in Japan indicate the PKU prevalence in some Asian pop-

so much as to make learning and the accomplishment of simple tasks impossible. PKU has impaired Dena's physical development Her coordination and motor control are so affected by PKU that she cannot even jump rope, tie her shoes, or play jacks

. . . .
 . . . Her chances for marriage, for motherhood and for a satisfying life . . . have been destroyed.

Perhaps saddest of all is that Dena has been left with just enough intelligence to understand that something is very wrong with her. She can look around and see that her sister and others can do and feel and know and experience things that she cannot.

492 So. 2d at 108-09.

Failure to test for other diseases as required by state law can produce similar liability on the part of the physician and hospital. *See, e.g.*, *Bishop v. Jaworski*, 524 A.2d 1102 (R.I. 1987) (hypothyroidism; statute of limitations tolled during child's minority despite sovereign immunity claim by public hospital, implying that liability could be found against hospital).

¹⁷ M. AVERY & H. TAEUSCH, *SCHAFFER'S DISEASES OF THE NEWBORN* 537 (5th ed. 1984).

¹⁸ *National Screening Status Report*, *supra* note 11; *International Screening Status Report*, *supra* note 12.

¹⁹ N. HOLTZMAN, *NEWBORN SCREENING FOR GENETIC-METABOLIC DISEASES 2* (U.S. Dep't of Health, Educ. and Welfare Publication No. 77-5207, 1977). Others recommend treatment until at least 10 to 12 years of age. J. TUERCK, *supra* note 10, at 7.

²⁰ M. AVERY & H. TAEUSCH, *supra* note 17.

²¹ Naylor, *supra* note 9.

²² According to UNICEF, in 1987, there were 122,048,000 births in countries whose annual number of deaths of children under 5 years of age per 1,000 live births (U5MR) were classified as Very High (over 170), High (95-170), and Middle (31-94). UNICEF, *THE STATE OF THE WORLD'S CHILDREN 1989*, 94-95 (Table I) (1989) [hereinafter *STATE OF THE WORLD'S CHILDREN*]. These countries would generally be counted as developing or Third World countries. The U5MR for the United States was thirteen, with Finland and Sweden recording the lowest U5MR (seven). *Id.* at 95. Subsequent estimates in the text of the number of Third World infants born with a particular disease are based on rounding off the UNICEF number to 122,000,000.

ulations can be nearly as low as 1 in 500,000,²³ although pilot screening in China indicates a prevalence of 1 in 15,064.²⁴ With rapid technical improvement in methods for early detection of PKU, "[b]y the early 1970s, mass screening for PKU had become routine in the United States and throughout most of the developed world."²⁵ Today, PKU screening is regarded as an essential component of public health in those affluent countries. According to one scientific commentator:

Screening programs for the detection of phenylketonuria (PKU) in newborns are now so widespread and the benefits to society at large so generally accepted that any developed country without a PKU screening program might be regarded as not having achieved the best possible standard of preventive medical care.²⁶

2. *Maple syrup urine disease* (MSUD), sometimes called branched-chain ketoaciduria, is caused by deficiencies in an enzyme system and usually leads to convulsions and death rapidly after birth.²⁷ In the United States, nearly half of the jurisdictions test all neonates for MSUD.²⁸ Unless there is early detection and effective treatment, only five to ten percent of infants with MSUD live, and they become severely retarded.²⁹ These neonates are considered to be medical emergencies who require immediate treatment.³⁰ Prevalence estimates vary from 1 in 150,000 in the Northwestern United States³¹ to 1 in 224,000 infants worldwide.³² The latter rate suggests that approximately 545 MSUD infants are born annually in the Third World.³³

²³ The precise reported prevalence is 1:450,840. Tada, Tateda, Arashima, Sakai, Kitagawa, Aoki, Suwa, Kawamura, Oura, & Takesada, *Follow-up Study of a Nationwide Neonatal Metabolic Screening Program in Japan*, 142 EUR. J. PEDIATRICS 204 (1984) [hereinafter Tada].

²⁴ Rui-Guan Chen, Da-Long Qian, Xue-Fan Gu, Xin-Shi Pan, Ming Shun, & Di Guo, *Results of the Neonatal Screening in Shanghai, China*, in ADVANCES IN NEONATAL SCREENING 477 (B. Therrell, Jr. ed. 1987) [hereinafter Chen].

²⁵ Naylor, *supra* note 9. In 1977 Japan initiated mass neonatal screening for PKU and five other disorders. Tada, *supra* note 23.

²⁶ Veale, *Screening for Phenylketonuria*, in NEONATAL SCREENING FOR INBORN ERRORS OF METABOLISM 7 (H. Bickel, et al. eds. 1980).

²⁷ R. BEHRMAN & R. Kliegman, *ESSENTIALS OF PEDIATRICS* 141 (1990).

²⁸ *National Screening Status Report*, *supra* note 11.

²⁹ Naylor, *supra* note 9, at 235.

³⁰ *Id.* at 234-35.

³¹ J. Tuerck, *supra* note 10, at 2 (Table I).

³² Naylor & Guthrie, *Newborn Screening for Maple Syrup Urine Disease (Branched-chain Ketoaciduria)*, 61 PEDIATRICS 2 (1968).

³³ See *supra* note 22.

3. *Hypothyroidism*, not primarily a genetic disorder, is caused by defects in pituitary or hypothalamic glandular function³⁴ that produce retardation in physical and mental growth.³⁵ Like PKU, congenital hypothyroidism is included in all American screening programs.³⁶ Treatment with synthetic hormones is a successful preventive measure.³⁷ The frequent occurrence of congenital hypothyroidism, 1 in 4,000 infants,³⁸ makes it the disorder most commonly found in the general population of newborns that is the subject of screening programs. Applying this prevalence rate to developing countries suggests an annual number of newborns with congenital hypothyroidism of 30,500.³⁹

4. *Galactosemia* is caused by an enzyme deficiency which produces severe and irreversible liver and brain damage,⁴⁰ and may cause death within one or two weeks of birth.⁴¹ Thirty-seven American states include galactosemia in their neonate screening tests.⁴² These newborns, too, are considered medical emergencies. Treatment consists of eliminating all milk and milk products from the diet.⁴³ The worldwide prevalence of galactosemia is said to be 1 in 50,000;⁴⁴ it occurs somewhat less frequently in the United States.⁴⁵

³⁴ Naylor, *supra* note 9, at 236-37.

³⁵ R. BEHRMAN & R. KLIEGMAN, *supra* note 27, at 595-97.

³⁶ *National Screening Status Report*, *supra* note 11.

³⁷ Naylor, *supra* note 9, at 236.

³⁸ *Id.*; see J. TUERCK, *supra* note 10, at 2. It is reported to occur somewhat more frequently in Israel (1:3244), where the researchers suggest that the higher prevalence may be due to a high rate of consanguinity within both Jewish and Arab populations. See Sack, Kletter, Amado, & Akstein, *Screening for Neonatal Hypothyroidism in Israel During a 4-year Period*, 21 ISRAEL J. MED. SCI. 485, 489 (1985) (Of 538,656 newborns screened in Israel from May 1978 through April 1984, 166 were diagnosed as having neonatal hypothyroidism.). A limited gene pool is also cited as responsible for high rates of sickle cell disease in some parts of Saudi Arabia. Al-Awamy, Al-Muzan, Al-Turki, & Serjeant, *Neonatal Screening for Sickle Cell Disease in the Eastern Province of Saudi Arabia*, 78 TRANSACTIONS ROYAL SOC'Y TROPICAL MED. & HYGIENE 792, 793-94 (1984) [hereinafter Al-Awamy]; see also Rosenthal, Addison, & Price, *Congenital Hypothyroidism: Increased Incidence in Asian Families*, 63 ARCHIVES OF DISEASE IN CHILDHOOD 790 (1988) (explaining increased incidence of hypothyroidism as a matter of consanguinity).

³⁹ See *supra* note 22.

⁴⁰ M. AVERY & H. TAEUSCH, *supra* note 17, at 529.

⁴¹ J. TUERCK, *supra* note 10, at 9.

⁴² *National Screening Status Report*, *supra* note 11.

⁴³ M. AVERY & H. TAEUSCH, *supra* note 17, at 533.

⁴⁴ *Id.* at 529.

⁴⁵ Occurrence in the United States could range from a frequency of 1:60,000 (J. TUERCK, *supra* note 10, at 2 (Table I)) or perhaps as infrequently as 1:75,000 (N.Y. STATE DEP'T OF HEALTH, NEWBORN SCREENING: FOR YOUR BABY'S HEALTH (1987) (brochure for new parents)).

The estimated number of galactosemic Third World infants born annually is 2,440.⁴⁶

5. *Homocystinuria*, another enzyme deficiency, can cause brain damage, mental retardation, dislocation of the optic lens, and skeletal abnormalities.⁴⁷ Twenty-one American states currently screen for homocystinuria.⁴⁸ Treatment requires pharmacological doses of vitamin B₆ or a diet controlled for certain key substances.⁴⁹ World-wide screening of more than 20 million infants indicated a prevalence of 1 in 200,000 for this disorder,⁵⁰ and an annual number of affected Third World infants of 610.⁵¹ Estimates for the United States closely match the international rate.⁵²

6. *Biotinidase deficiency* results from defective activity of an enzyme that links biotin to other substances. A failure to diagnose and treat the deficiency causes permanent neurological damage and mental retardation; however, early diagnosis and treatment with pharmacological doses of biotin produce "marked improvement."⁵³ Only ten American states screen for biotinidase deficiency.⁵⁴ Prevalence is estimated to be as low as 1 in 60,000⁵⁵ and as high as 1 in 48,000 infants,⁵⁶ suggesting an annual Third World afflicted newborn population of between 2,033 and 2,542.⁵⁷

7. *Sickle cell disease and sickle cell trait* are both classed as hemoglobinopathies, or defects in a blood constituent. The disease can cause severe anemia, pneumonia, severe infections, chronic organ failure, and other chronically debilitating complications affecting general health and development.⁵⁸ There is no therapy for this disease at the present time.⁵⁹ Despite this, twenty-eight American states now screen for the sickle cell diseases⁶⁰ and several others are

⁴⁶ See *supra* note 22.

⁴⁷ R. BEHRMAN & R. KLEIGMAN, *supra* note 27, at 139-40.

⁴⁸ *National Screening Status Report*, *supra* note 11.

⁴⁹ Naylor, *supra* note 9, at 235.

⁵⁰ *Id.*

⁵¹ See *supra* note 22.

⁵² J. TUERCK, *supra* note 10, at 2 (Table I) (1:150,000); N.Y. STATE DEP'T OF HEALTH, *supra* note 44 (1:225,000).

⁵³ Naylor, *supra* note 9, at 238.

⁵⁴ *National Screening Status Report*, *supra* note 11.

⁵⁵ J. TUERCK, *supra* note 10, at 2 (Table I).

⁵⁶ Naylor, *supra* note 9, at 238-39.

⁵⁷ See *supra* note 22.

⁵⁸ R. BEHRMAN & R. KLEIGMAN, *supra* note 27, at 505-07.

⁵⁹ *Id.*

⁶⁰ *National Screening Status Report*, *supra* note 11.

in the process of developing sickle cell screening.⁶¹ Neonatal screening for these disorders is generally justified on the grounds that early knowledge leads to a better management of symptoms and complications by parents and medical personnel.⁶² In the United States, sickle cell disease occurs in blacks at a rate of 1 in 500. Ten percent of afflicted persons are from other races.⁶³ In the sub-Saharan African and Caribbean nations with predominantly black populations, large numbers of afflicted infants would be anticipated. The prevalence in countries in which there has been a widespread miscegenation of the population, such as Brazil, appears to be unknown.

8. *Congenital adrenal hyperplasia (CAH)* is an inherited disease that causes virilization of female infants, dehydration, and shock. In the Northwestern United States it occurs in about 1 in 14,000 infants, although it is much more prevalent in some populations (1:282 in Yupik Eskimos).⁶⁴ CAH can be treated with hydrocortisone,⁶⁵ and is included in the screening programs of four American states.⁶⁶

9. *Tyrosinemia* develops as a result of the immaturity of liver enzymes, and high protein intake, or possibly a deficiency in the amount of vitamin C intake of the mother or infant.⁶⁷ In its severe form, tyrosinemia produces death in the first weeks of life.⁶⁸ Newborns with a less severe case can survive until adulthood, but may experience retardation, a failure to thrive, rickets, and a serious clotting disorder.⁶⁹ Tyrosinemia is reported to appear in about one in ten prematurely born infants;⁷⁰ in the general population of newborns it may be close to 1 in 3,000.⁷¹ Although one in ten babies was born prematurely in the United States in 1986,⁷² only six states

⁶¹ *Id.*

⁶² Naylor, *supra* note 9, at 238.

⁶³ *Id.*

⁶⁴ J. TUERCK, *supra* note 10, at 2 (Table I).

⁶⁵ *Id.*

⁶⁶ *National Screening Status Report, supra* note 11.

⁶⁷ J. TUERCK, *supra* note 10, at 12.

⁶⁸ *Id.*

⁶⁹ *Id.*

⁷⁰ *Id.*

⁷¹ One study reports on prevalence in premature infants, but states that in the general population of newborns tyrosinemia occurs in "some" cases. J. TUERCK, *supra* note 10, at 12. A study of newborns screened in Georgia for tyrosinemia reports a prevalence of 1:3,158. Fernhoff, Fitzmaurice, Milner, McEwen, Dembure, Brown, Wright, Acosta, & Elsas, *Coordinated System for Comprehensive Newborn Metabolic Screening*, 75 S.J. MED. 529, 530 (1982).

⁷² D. HUGHES, K. JOHNSON, S. ROSENBAUM, & J. LIU, *THE HEALTH OF AMERICA'S CHILDREN* 7 (1989).

currently screen for tyrosinemia.⁷³ Treatment, which starts with a restricted diet, must be administered in a major medical center.⁷⁴

10. *Acquired immunodeficiency syndrome (AIDS)* is a sexually transmitted disease caused by a virus (HIV) and is nearly always fatal. No cure is known at the present time for AIDS, nor is there accurate knowledge of its incidence. Prenatal exposure is the most common route of HIV infection in children.⁷⁵ In order to obtain epidemiological knowledge of its prevalence in the population of women of child-bearing age in the United States, the states of New York⁷⁶ and Massachusetts⁷⁷ have been screening neonates for HIV antibodies. Screening of newborn blood samples indicates the prevalence was 0.2% in Massachusetts and 0.8% in New York state, but was more than 1.6% in some parts of New York City.⁷⁸ A recently announced federal program is conducting a similar screening procedure on one third of all the neonates in the country.⁷⁹

The screening process requires testing a small blood sample from the newborn, pursuing further diagnostic procedures when required, and instituting the necessary treatment. Quality control issues, particularly relating to timing, arise at every step of this process.⁸⁰

III. THE MEANING OF "HEALTH"

Neither the Convention itself nor any of the other international instruments discussed below contains a legal definition of "health." Nevertheless, in 1948, the World Health Organization (WHO), introduced an internationally accepted definition of this term: "a state of complete physical, mental and social well-being and not merely

⁷³ *National Screening Status Report*, *supra* note 11.

⁷⁴ J. TUERCK, *supra* note 10, at 12.

⁷⁵ Falloon, Eddy, Wiener, & Pizzo, *Human Immunodeficiency Virus Infection in Children*, 114 J. PEDIATRICS 1, 2-3 (1989).

⁷⁶ N.Y. STATE DEP'T OF HEALTH, 1988-89 ANNUAL REPORT 21 (1989).

⁷⁷ See Hoff, Berardi, Weiblen, Mahoney-Trout, Mitchell, & Grady, *Seroprevalence of Human Immunodeficiency Virus Among Childbearing Women*, 318 NEW ENG. J. MED. 525 (1988).

⁷⁸ *Id.* at 528-29.

⁷⁹ Centers for Disease Control, Center for Infectious Diseases, AIDS Program, Press Release (Aug. 23, 1988); see Rochester (N.Y.) Democrat Chronicle, Aug. 23, 1988, at 1, col. 1. In addition to the disorders listed in the text, one American state screens for toxoplasmosis (Massachusetts), and three for cystic fibrosis (Colorado, Wisconsin, and Wyoming). *National Screening Status Report*, *supra* note 11.

⁸⁰ See, e.g., J. TUERCK, *supra* note 10, at 15. In one study it was reported that errors in this process accounted for one third of the affected infants whose disorders were undetected by the screening program. *Id.*

the absence of disease or infirmity.”⁸¹ Whereas attaining this state is a sound objective, it cannot readily be incorporated as the content of a legal right, if for no other reason than that the genetic makeup of individuals may preclude their ability to achieve health in this sense. It is not rational, therefore, to impose a legal duty on governments (or anyone else) to achieve a result that may well be genetically impossible.⁸² Even more narrowly conceived—as the absence of disease, for example—the duty to provide “health” may still require something no government can deliver, since there is no way to guarantee each individual’s protection against the whole range of disease-causing agents.

Nevertheless, it is feasible to conceive of a treaty right to health as requiring the establishment, support and guaranteed access to health-related programs, designed to make progress toward health objectives, without a firm duty to achieve those objectives for each individual. The steps to be taken under Article 24 of the Convention are generally of this nature, reflecting developments in other bodies of human rights law.⁸³ Moreover, because a right to health cannot relate to the health status of any particular person, an international monitoring or enforcement system that would rely on individual complaints⁸⁴ would be ineffective. Unless an international class ac-

⁸¹ Constitution of the World Health Organization, 14 U.N.T.S. 186 (1948), at preamble, *reprinted in* WHO, BASIC DOCUMENTS 1 (37th ed., 1988). This definition was included in the Declaration of Alma-Ata, *reprinted in The Alma-Ata Conference on Primary Health Care*, 32 WHO CHRONICLE 409, 428 (1978) [hereinafter *Primary Health Care*]. The Alma-Ata International Conference on Primary Health Care was held from September 6–12, 1978 at Alma-Ata, USSR. *Id.* at 410. The conference was convened jointly by WHO and UNICEF. *Id.* The World Health Assembly, the annual meeting of delegates from all WHO member States, endorsed the Alma-Ata Report and Declaration in 1979. WHO, GLOBAL STRATEGY FOR HEALTH FOR ALL BY THE YEAR 2000 11 (1981) [hereinafter WHO GLOBAL STRATEGY]. The Report has since been the conceptual focus of WHO’s work.

⁸² WHO made this point in response to the health-related text in the first Polish draft of the Convention: “We have some difficulties with the provision ‘he shall be entitled to grow and develop in health’,[sic] because the right to be healthy, as the provision seems to suggest, appears to be unrealistic.” *Question of a Convention on the Rights of the Child; Report of the Secretary-General* at 311, U.N. Doc. E/CN.4/1324 (1978) [hereinafter *Question of Convention*].

⁸³ *Cf.* Trubeck, *Economic, Social, and Cultural Rights in the Third World: Human Rights Law and Human Needs Programs*, in HUMAN RIGHTS IN INTERNATIONAL LAW: LEGAL & POLICY ISSUES 205, 206–07 (T. Meron ed. 1985) (“I believe that international law is moving towards the creation of obligations which bind states to undertake programs to guarantee minimum levels of economic, social and cultural well-being to all citizens of this planet, and progressively to increase such well-being.”).

⁸⁴ These can be communications made to a committee, as under the *Optional Protocol to the International Covenant on Civil and Political Rights* (G.A. Res. 2200, 21 U.N. GAOR Supp. (No. 16) at 59, U.N. Doc A/6316 (1966)) or petitions seeking judicial redress as under Article 25 of the European Convention for the Protection of Human Rights and Fundamental Freedoms (Nov. 4, 1950, 213 U.N.T.S. 221 (*entered into force* Sept. 3, 1953)).

tion is developed whereby individual circumstances can be used to highlight broad programmatic deficiencies, a system in which States Parties report their implementation of treaty rights to an international monitoring body, as is provided for in the Convention,⁸⁵ is appropriate.

IV. THE EVOLUTION OF ARTICLE 24

A. *The World Health Organization*

The subject of health first appeared in major post-World War II international documents in the now-familiar language of international human rights. A right to health was one of the earliest rights to have been proclaimed by the international community. It appeared with the most popularly declared human rights of our era—equality and non-discrimination—in the preamble to the constitution of the newly formed World Health Organization (WHO):⁸⁶ “The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition.”⁸⁷

Although the WHO Constitution is a multilateral treaty and therefore a legal document containing duties assumed by member

⁸⁵ The monitoring machinery is provided for in Part II of the Convention. At its core is a Committee on the Rights of the Child (Committee), composed of 10 independent experts elected by the States Parties. *Convention*, *supra* note 4, at art. 43(1),(2),(3). The Committee normally meets annually for a period to be set by the States Parties, subject to the approval of the General Assembly. *Id.* at art. 43(10). This approval is necessary since the United Nations pays the expenses required by the Committee's work. *Id.* at art. 43(11). Under Article 44, the States Parties submit reports to the Committee “on the measures they have adopted which give effect to the rights recognized [by the Convention] . . . and on the progress made on the enjoyment of those rights.” *Id.* at art. 44(1). These reports are to “indicate factors and difficulties, if any, affecting the degree of fulfillment of the obligations under the present Convention. Reports shall also contain sufficient information to provide the Committee with a comprehensive understanding of the implementation of the Convention in the country concerned.” *Id.* at art. 44(2). If additional information is required, the Committee is authorized to seek it. *Id.* at art. 44(4).

⁸⁶ Constitution of the World Health Organization, *supra* note 81. At a United Nations Conference on International Organizations in 1945, unanimous approval was given to a motion by China and Brazil to create an autonomous international health body in the United Nations system. WHO, WHO: WHAT IT IS, WHAT IT DOES 1 (1988). WHO became one of the specialized agencies referred to in Article 57 of the United Nations Charter. *See UNITED NATIONS CHARTER* art. 57.

⁸⁷ Constitution of the World Health Organization, *reprinted in* WHO, BASIC DOCUMENTS, *supra* note 81, at 1.

governments,⁸⁸ the preamble itself is merely a statement of principles. It creates no legal duty on governments to adopt specific health programs, such as newborn screening, or to recognize in any particular way the right to health that it declares to be fundamental for every human being. Children are specifically referred to in two places in the WHO Constitution,⁸⁹ but again without creating any implication of legal duties on their behalf.

The English text of this assertion that health is a human right is, moreover, highly ambiguous. It is unclear whether the phrase "highest attainable standard of health" refers to what is attainable in light of the capacities of each individual or, on the other hand, to what is attainable by a particular country in the context of its resources and priorities.⁹⁰ Furthermore, this part of the preamble is long on enthusiasm, but short on specifics. It fails to suggest what the "highest attainable standard of health" implies substantively, despite the fact that infant mortality is the internationally recognized indicator of a nation's health.

Even if the WHO Health Assembly, the health organization's policy-making body, were to endorse a set of programs such as newborn screening as being a necessary component of the human right declared in the preamble, the core duty of the treaty would

⁸⁸ See, e.g., Constitution of the World Health Organization, *supra* note 81, at art. 26. "Each Member undertakes that it will, within eighteen months after the adoption by the Health Assembly of a convention or agreement, take action relative to the acceptance of such convention or agreement." *Id.*

⁸⁹ The WHO Constitution's preamble provides that "[h]ealthy development of the child is of basic importance; the ability to live harmoniously in a changing total environment is essential to such development." Constitution of the World Health Organization, *supra* note 81, at preamble. Article 2 of the WHO Constitution provides that "[i]n order to achieve its objective, the functions of the Organization shall be: . . . (1) to promote maternal and child health and welfare and to foster the ability to live harmoniously in a changing total environment." *Id.* at art. 2.

⁹⁰ The French text appears to resolve the ambiguity in favor of individual capacity: "La possession du meilleur etat de sante qu'il est capable d'atteindre constitue l'un des droits fondamentaux de tout etre humain, quelles que soient sa race, sa religion, ses opinions politiques, sa condition economique ou sociale." Constitution de L'Organisation Mondiale de la Sante, 14 U.N.T.S. 204 (1948). The English text's ambiguity can also be found in some American statutes. See, e.g., MD. HEALTH-GEN. CODE ANN. § 13-102 (1990) ("The General Assembly finds that: (1) Everyone in this State is entitled to the highest level of health care attainable and protection from inadequate health services."). The Comprehensive Health Planning and Public Health Services Amendments of 1966 (Pub. L. No. 89-749, 80 stat. 1180 (1966)), Findings and Declaration of Purpose, on the other hand, is like the French text in speaking of individual capacity: "The Congress declares that the fulfillment of our national purpose depends on promoting and assuring the highest level of health attainable for every person . . ." *Id.*

not oblige member governments to recognize and implement a right to screening, but only to *act* on the endorsement within eighteen months. They need not accept it.⁹¹ In any event, the Health Assembly has made no recommendation on newborn screening.

Importantly, it is unclear that the preamble's reference to health as a human right is even meant to include children, despite its reference to "every human being." It would be erroneous to assume that documents in the field of human rights that are drafted in terms of "everyone" or "anyone" always provide rights for children. The Covenant on Civil and Political Rights, for example, recognizes the right of "everyone" to be able "to choose his residence."⁹² Yet it is unlikely that this guarantee assures that an unaccompanied five-year-old can set up his or her own residence. Similarly, although the Universal Declaration states that "[e]veryone has the right to take part in the government of his country, directly or through freely chosen representatives,"⁹³ few would contend that there can be no minimum age for voting. It is equally uncontentious, however, that the phrase "no one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment,"⁹⁴ includes children. Insofar as the right to health may imply the autonomy to choose or decline medical treatment, such as immunization or the abortion of a fetus carried by a female child, the extension of this right to children is not clear.⁹⁵

Perhaps most crucial for present purposes is the nature of the role that WHO has adopted under these texts. The public health policy it has pursued since 1976, called Primary Health Care (PHC),⁹⁶ is a concept that has been adopted as a fundamental health policy by most of the world community.⁹⁷ The goal of PHC is

⁹¹ Constitution of the World Health Organization, *supra* note 81, at art. 26.

⁹² *International Covenant on Civil and Political Rights*, art. 12(1), G.A. Res. 2200 (XXI), 21 GAOR Supp. (No. 16) at 52, 54, U.N. Doc. A/6316 (1966).

⁹³ *Universal Declaration of Human Rights*, art. 21(1), signed Dec. 10, 1948, G.A. Res. 217A (III), U.N. Doc. A/810, at 71 (1948), reprinted in *BASIC DOCUMENTS ON HUMAN RIGHTS* 21-27 (I. Brownlie ed. 1981).

⁹⁴ *Id.* at art. 5.

⁹⁵ The additional reference in the WHO Constitution's preamble to the healthy development of the child being "of basic importance" (Constitution of the World Health Organization, *supra* note 81, at preamble) may further support the belief that the preamble's concept of the human right to health does not include children insofar as everything "of basic importance" may not be one of the "fundamental human rights."

⁹⁶ See *Primary Health Care*, *supra* note 81. PHC is referred to twice in the health provisions of the Convention. See *Convention*, *supra* note 4, at art. 24(2)(b)-(c).

⁹⁷ See, e.g., *Implementation of the International Covenant on Economic, Social and Cultural*

"Health for All by the Year 2000."⁹⁸ To achieve this goal, WHO has the responsibility of extending technical assistance to each country in a cooperative effort to develop an assessment of needs for PHC, of indicators of a population's health status and progress, and of national monitoring of achievements in approaching the goal.⁹⁹ This work of WHO in improving health has appropriately been described as a "totally 'non-rights' approach,"¹⁰⁰ a characterization which emphasizes that all of WHO's accomplishments have been gained without reliance on the international law which provides health rights. The health partnership between WHO and individual States is thus a negotiated and consensual relationship that is not structured by international legal duties in the field of health.

In this respect, WHO functions similarly to the United Nations Children's Fund (UNICEF), the other major international agency focusing on improving the health of children. The General Assembly resolution establishing UNICEF makes this orientation explicit: "The Fund shall not engage in activity in any country except in consultation with, and with the consent of, the Government concerned."¹⁰¹

Rights; Initial Reports Submitted by States Parties to the Covenant, in Accordance with the Second Stage of the Programme Established by Economic and Social Council Resolution 1988 (LX), Concerning Rights Covered by Articles 10-12: France, U.N. Doc. E/1986/3/Add.10 (1987).

⁹⁸

WHO's fourth decade opened with a revolutionary decision that was intended to dominate its work until the turn of the century; its members undertook to make a giant effort to enable people everywhere to become healthy enough to lead social and economically productive lives. The collective goal is known as 'health for all by the year 2000'.^[sic] The emphasis is on equity—health for all—and on urgency, clearly conveyed by the deadline.

WHO, *FOUR DECADES OF ACHIEVEMENT* 23 (1988).

⁹⁹ *Id.* at 22-39.

¹⁰⁰ Harris, *Commentary by the Rapporteur on the Consideration of States Parties' Reports and International Cooperation*, 9 HUMAN RIGHTS QUARTERLY 147, 153 (1987).

¹⁰¹ *Establishment of an International Children's Emergency Fund*, G.A. Res. 57(I), U.N. Doc. No. A/64/Add.1, at 90 (1946). "By Res. 802(VIII) of 6 October 1953 the GA decided to change the name of the organization [from the United Nations International Children's Emergency Fund] to the United Nations Children's Fund, retaining the symbol UNICEF." INTERNATIONAL ORGANIZATION AND INTEGRATION, Vol. I.A., at 11.4.a (1981).

The activities of UNICEF have demonstrated what can be accomplished in the context of cooperation. Although initially devoted in 1946 to assisting children who had been war victims, it has become the major actor on the world scene in promoting the survival and health of children in developing countries. With the consent of affected governments, its impact has been primarily through programs for immunizing children against the infectious diseases that were, in the mid-1970s, killing more than 4.5 million children annually. STATE OF THE WORLD'S CHILDREN, *supra* note 22, at 4. It has also promoted oral rehydration therapies which can potentially prevent 3.5 million of the 5 million annual deaths of children from diarrhoeal diseases in the Third World. *Id.* at 3; see also G. WILLIAMS, A SIMPLE SOLUTION:

This "non-rights approach" operates to the exclusion of one that is rights related. Along with other Specialized Agencies of the United Nations,¹⁰² WHO has been assigned two crucial roles in the implementation and monitoring of rights declared in the International Covenant on Economic, Social and Cultural Rights¹⁰³ (Economic Covenant): (1) assisting States Parties in developing the health care programs that serve to implement the individual's right to health care under Article 12; and (2) reporting to the Economic and Social Council (ECOSOC) on the progress achieved by States Parties in protecting the right to health,¹⁰⁴ thereby providing the Council with information that is crucial to its role in monitoring activity under the Economic Covenant. WHO no longer performs the second role. It submitted one very general report to ECOSOC in 1980 pursuant to the Economic Covenant¹⁰⁵ and none since then, having otherwise abandoned any ancillary responsibility in monitoring States Parties' compliance with their international legal obligations in the field of health.¹⁰⁶ As a result, it is difficult to discern WHO's views on the nature and scope of the right to health under international law.

In 1973, however, when WHO was still considered to be involved with the legal rights of health, the World Health Assembly requested its Director-General to prepare a study on health aspects of human rights in light of scientific and technological developments.¹⁰⁷ The resulting report appeared to express a belief that

ORAL REHYDRATION IS AVERTING CHILD DEATH FROM DIARRHOEAL DEHYDRATION (1987). In 1988, UNICEF reported that its efforts were saving nearly 40,000 children each week. STATE OF THE WORLD'S CHILDREN, *supra* note 22, at 1.

It is, of course, impossible to identify how much of this success might be attributable to the influence of legal duties imposed by treaty obligations, how much can be traced to the impact of a broad consensus on the centrality of the health of children, and how important the skills of UNICEF have been in organizing and operating these programs.

¹⁰² UNICEF is not one of the Specialized Agencies.

¹⁰³ *International Covenant on Economic, Social and Cultural Rights*, G.A. Res. 2200 (XXI), 21 U.N. GAOR Supp. (No. 16) at 49, U.N. Doc. A/6316 (1966), *reprinted in* BASIC DOCUMENTS ON HUMAN RIGHTS, *supra* note 93, at 118-27. The health provisions of this covenant are discussed *infra* p. 20.

¹⁰⁴ Trubeck, *supra* note 83, at 219-23.

¹⁰⁵ *Implementation of the International Covenant on Economic, Social and Cultural Rights: Note by the Secretary-General*, U.N. Doc. E/1980/24 (1980). In regard to children's health, this WHO report does little more than note that data on worldwide infant mortality and morbidity are scarce and cite World Health Assembly resolutions urging governments to look after children's health.

¹⁰⁶ Trubeck, *supra* note 83, at 244-45.

¹⁰⁷ World Health Assembly Res. 23.41, *reprinted in* 1 WHO, HANDBOOK OF RESOLUTIONS AND DECISIONS OF THE WORLD HEALTH ASSEMBLY AND THE EXECUTIVE BOARD 501 (1973).

whether a program would be included in the right to health would depend on the stage of a particular nation's economic development and the number of potential beneficiaries of the program. In the context of addressing the question of infant screening (for PKU), the report concluded: "It is evident that only economically developed countries can contemplate nationwide programmes for protecting 1 in 10,000 infants from developing preventable mental defect [sic] and for providing special diets to this end."¹⁰⁸

The WHO statement does not make clear whether, even in "economically developed countries," the one child in 10,000 has a human right to screening for medical disorders. It is our contention, elaborated below, that in the affluent countries there is such a right. Moreover, it cannot be assumed that the right does not exist in the developing world as well.

B. *The Universal Declaration of Human Rights*¹⁰⁹

Two years after the WHO Constitution was signed, the General Assembly of the United Nations adopted, without dissent, the Universal Declaration of Human Rights (Universal Declaration), which, along with the United Nations Charter,¹¹⁰ formally initiated the international human rights movement. It included a paragraph referring to health, but in the amorphous context of heterogeneous rights:

Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.¹¹¹

This is, at best, an awkward reference to a children's right to health. Even accepting that such a right may be found in the Universal Declaration, it should be noted that although some parts of the

¹⁰⁸ WHO, HEALTH ASPECTS OF HUMAN RIGHTS, WITH SPECIAL REFERENCE TO DEVELOPMENTS IN BIOLOGY AND MEDICINE 23 (1976) [hereinafter HEALTH ASPECTS].

¹⁰⁹ *Universal Declaration of Human Rights*, *supra* note 93.

¹¹⁰ The preamble of the Charter asserts the determination of the world community "to reaffirm faith in fundamental human rights, in the dignity and worth of the human person, in the equal rights of men and women and of nations large and small." UNITED NATIONS CHARTER, *supra* note 86, at preamble. The Charter further identifies among the purposes of the United Nations "[t]o achieve international cooperation . . . in promoting and encouraging respect for human rights and for fundamental freedoms . . ." *Id.* at art. 1(3).

¹¹¹ *Universal Declaration of Human Rights*, *supra* note 93, at art. 25(1).

Declaration have been so widely recognized that they have become customary international law, and therefore binding on all nations that have not opposed them, there is no indication that the right to health has been recognized in this manner. Like the preamble to the WHO Constitution, this part of the Universal Declaration imposes no legal duty on any government in regard to a right to health for children.¹¹²

C. *The Declaration on the Rights of the Child*

The General Assembly of the United Nations has spoken of health on several subsequent occasions.¹¹³ The most relevant statement is the 1959 Declaration on the Rights of the Child. Principle 4 of the Declaration states:

¹¹² Other human rights for children are mentioned, albeit with similarly great generality, in the 1948 Declaration. According to Article 25(2) of that Declaration, "Motherhood and childhood are entitled to special care and assistance. All children, whether born in or out of wedlock, shall enjoy the same social protection." *Id.* This is referred to in paragraph 4 of the Convention preamble: "Recalling that, in the Universal Declaration of Human Rights, the United Nations has proclaimed that childhood is entitled to special care and assistance." *Convention, supra* note 4, at preamble.

¹¹³ At least four General Assembly Resolutions mention or imply a right to health. *Declaration on Social Progress and Development*, arts. 10(d), 11(b), 19(a), G.A. Res. 2542 (XXIV), 24 U.N. GAOR Supp. (No. 30) at 49, U.N. Doc. A/7630 (1969); *Declaration on the Rights of Mentally Retarded Persons*, art. 2, G.A. Res. 2856 (XXVI), 26 U.N. GAOR, Supp. (No. 29) at 93, U.N. Doc. A/8429 (1971); *Declaration on the Rights of Disabled Persons*, art. 6, G.A. Res. 3447 (XXX), 30 U.N. GAOR, Supp. (No. 34) at 88, U.N. Doc. A/10034 (1975); *Declaration on the Human Rights of Individuals Who Are Not Nationals of the Country in Which They Live*, art. 8(1)(c), G.A. Res. 40/144, 40 U.N. GAOR Supp. (No. 53), U.N. Doc. A/40/53 (1985).

At the present time a right to health or medical treatment is also declared in three additional international human rights treaties, none of which specifically mentions children. See *International Convention on Elimination of All Forms of Racial Discrimination*, art. 5(e)(4), 660 U.N.T.S. 195 (1966), *reprinted in* INTERNATIONAL ORGANIZATION AND INTEGRATION, *supra* note 101, at 12.3.a (immediate and unqualified duty to "prohibit and eliminate racial discrimination in all its forms" in the enjoyment of "[t]he right to public health, medical care, social security and social services"); *Convention on the Elimination of All Forms of Discrimination Against Women*, arts. 11(1), 12(1), 14(2), G.A. Res. 34/180, 34 U.N. GAOR Supp. (No. 46) at 193, U.N. Doc. A/34/46 (1979) (enjoyment of health rights "on a basis of equality of men and women"); *International Labour Organization, Forced Labour Convention*, (No. 29) art. 17(1), 39 U.N.T.S. 55 (1930) (duty to provide for health and sanitation needs of work performed under compulsion that is not "forced labor," such as that performed pursuant to military service). It also appears in four regional human rights documents. *European Social Charter*, art. 11, European Treaty Series, No. 48, 12 *European Yearbook* 397 (1961); *Draft Protocol Addendum to American Convention on Human Rights (Pact of San Jose de Costa Rica, 1969)*, art. 11 (1986); *African (Banjul) Charter on Human and Peoples' Rights*, art. 16, O.A.U. Doc. CAB/LEG/67/3 Rev. 5, *reprinted in* 21 *I.L.M.* 58 (1982); *Declaration of Basic Duties of ASEAN [Association of South East Asian Nations] Peoples and Governments*, art. 5(3), (7), adopted by the First General Assembly of the Regional Council on Human Rights in Asia, Dec. 9, 1983 at Djakarta, Indonesia.

The child shall enjoy the benefits of social security. He shall be entitled to grow and develop in health; to this end, special care and protection shall be provided both to him and his mother, including adequate pre-natal and post-natal care. The child shall have the right to adequate nutrition, housing, recreation and medical services.¹¹⁴

This Principle is not referred to in the Convention, although one of the Declaration's other provisions is quoted in full in the preamble to the Convention. The insertion of that quotation was the result of an amendment to the preamble adopted at second reading in December 1988 that was designed to express the concern of several delegations for the protection of fetal rights.¹¹⁵

As a General Assembly resolution, the Declaration of the Rights of the Child imposes no legal duties on governments. In addition, no claim has been made that the Declaration as a whole, or Principle 4 in particular, has passed into customary international law. Taken together, the WHO Constitution, the Universal Declaration, and the Declaration on the Rights of the Child represent the kind of broad international consensus that can be relied on by agencies such as WHO and UNICEF when they seek cooperation of individual states in pursuing their health programs. These documents, however, lack both the clarity and the force of law.

D. *The International Covenant on Economic, Social and Cultural Rights*

Unlike the WHO preamble, the Universal Declaration, and the Declaration on the Rights of the Child, the Economic Covenant¹¹⁶ creates legal duties for its States Parties, and it is often cited as one of the three core documents expressing an international consensus on human rights law.¹¹⁷ The human rights which the Economic

¹¹⁴ *Declaration of the Rights of the Child*, Principle 4, G.A. Res. 1386 (XIV), 14 GAOR Supp. (No. 16), at 19, U.N. Doc. A/4354 (1959), reprinted in BASIC DOCUMENTS ON HUMAN RIGHTS, *supra* note 93, at 108–10.

¹¹⁵ "Bearing in mind that, as indicated in the Declaration of the Rights of the Child, 'the child, by reason of his physical and mental immaturity, needs special safeguards and care, including appropriate legal protection, before as well as after birth.'" *Convention*, *supra* note 4, at preamble, para. 6.

¹¹⁶ *Supra* note 103.

¹¹⁷ Professor Henkin, referring to the Universal Declaration of Human Rights, *supra* note 93, the International Covenant on Civil and Political Rights, *supra* note 84, and the International Covenant on Economic, Social and Cultural Rights, *supra* note 103, collectively known as the International Bill of Rights, has concluded:

[I]t is individual civil-political rights as well as economic-social and cultural rights that are the law, not unmitigated collectivism or laissez faire. The idea of human rights is not an abstraction; it has specific content. What the world has accepted are

Covenant defines and the legal process it provides for monitoring their implementation are fundamental to an understanding of the Convention. Importantly, Article 12 of the Economic Covenant is the most direct ancestor of several provisions of the Convention, including the Article 24 right to health.

The right to health contained in the first paragraph of the Economic Covenant's Article 12 repeats the enthusiastic, vague, and ambiguous statement of the WHO Constitution: "The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health."¹¹⁸

This article, however, does set forth what steps the States Parties must take in order to "achieve the full realization of this right,"¹¹⁹ one of which directly addresses the health of children. Paragraph 2 of Article 12 requires those steps that are necessary for, *inter alia*, "[t]he provision for the reduction of the stillbirth rate and of infant mortality and for the healthy development of the child."¹²⁰ Reference to "the stillbirth rate" has been omitted from Article 24 of the Convention, and the provisions of Article 24 as a whole may be seen as an elaboration of "the healthy development of the child" phrase in Article 12(2)(a) of the Economic Covenant.¹²¹ Article 24 also reflects a somewhat more detailed and articulate expression of the consensus expressed in the WHO Constitution, the Universal Declaration, and the Declaration of the Rights of the Child.

The impact of Article 12 (and of all other rights that are "recognized" in the Economic Covenant) is, however, sharply qualified by Article 2(1):

the civil, political, economic, social and cultural rights set forth in the Universal Declaration and the international covenants.

Henkin, *Introduction*, to *THE INTERNATIONAL BILL OF RIGHTS 2* (L. Henkin ed. 1981). The idea of international consensus raises the question of whether, by virtue of the combined effect of the legally binding treaties, non-legally binding documents such as the General Assembly resolutions discussed in the text, and practice that has developed under them, a rule of customary international law has developed expressly protecting a child's right to health, or embodying a "best interests of the child" principle. Exploring that question is, however, beyond the scope of this paper.

¹¹⁸ *International Covenant on Economic, Social and Cultural Rights*, *supra* note 103, at art. 12(1). The language similarity is no coincidence. WHO took an active hand in drafting this article. See Alston, *The United Nations' Specialized Agencies and Implementation of the Covenant on Economic, Social and Cultural Rights*, 18 COLUM. J. TRANSNAT'L L. 79, 88 (1979).

¹¹⁹ *International Covenant on Economic, Social and Cultural Rights*, *supra* note 103, at art. 12(2).

¹²⁰ *Id.* at art. 12(2)(a).

¹²¹ *Id.*

Each State Party to the present Covenant undertakes to take steps, individually and through international assistance and co-operation, especially economic and technical, to the maximum of its available resources, with a view to achieving progressively the full realization of the rights recognized in the present Covenant by all appropriate means, including particularly the adoption of legislative measures.¹²²

“Progressive” implementation and “to the maximum of [a State Party’s] available resources” are interrelated concepts reflecting a wise policy. The Economic Covenant’s scheme recognizes that a State’s application of the maximum of its available resources to the health of its people might fall short of fulfilling every citizen’s “right to health.” Granting every person a legal right to health, for example, may be seen as implying duties to create conditions conducive to good health, facilities for responding to poor health, programs for preventing ill health—perhaps even nationwide neonatal screening for all detectable disorders. These are duties that imply so much public and private expenditure that fulfilling them must necessarily await the availability of the required resources. Simply to take the steps necessary to reduce infant mortality, as is expressly required by the Economic Covenant, may entail commitment of resources that are available only in the developed countries.¹²³

But the problems of determining what State obligations are created in the context of this policy are prodigious.¹²⁴ A central set of questions concerns the meaning of the phrase “to the maximum of its available resources” in Article 2(1). It is clear that a State has wide discretion both in determining the quantity of resources that are available for pursuing any of the State’s aims and in further deciding what portion of these constitute the maximum which it is able to devote to implementing the covenant. But as Phillip Alston and Gerard Quinn observe in *The Nature and Scope of State Parties’ Obligations under the International Covenant on Economic, Social and Cultural Rights*, “such discretion cannot be entirely open-ended or it would have the *de facto* effect of nullifying the existence of any real obligation.”¹²⁵ For there to be a legal duty and a legal right,

¹²² *Id.* at art. 2(1).

¹²³ See, e.g., NATIONAL COMMISSION TO PREVENT INFANT MORTALITY, *DEATH BEFORE LIFE: THE TRAGEDY OF INFANT MORTALITY* (1988).

¹²⁴ See Alston & Quinn, *The Nature and Scope of State Parties’ Obligations under the International Covenant on Economic, Social and Cultural Rights*, 9 HUM. RTS. Q. 156 (1987).

¹²⁵ *Id.* at 177.

the discretion must in some way be circumscribed. Furthermore, it would be difficult, if not impossible, for the agency charged with monitoring a State Party's compliance with its duties¹²⁶ to evaluate whether the State Party's determination of the best use of its maximum available resources is in compliance with its legal obligations under the Economic Covenant or is a violation of its undertakings.¹²⁷ This would be the case, for example, where a State Party determines that a maximum of its available resources will meet either the fiscal demands of the Article 12 right to health or of the Article 13 right to education, but not both in any significant degree.

A similar problem arises within each right provided by the Economic Covenant. If, for example, a State Party has one million dollars available to implement the right to health guaranteed by Article 12, may it legally use the entire amount to build one major hospital in its capital city instead of five health clinics in the countryside, or to improve industrial hygiene?¹²⁸ Alternatively, it may consider using the funds for initiating a newborn screening program to reduce infant mortality. Article 12 of the Economic Covenant is cast in broad general language that would accommodate all of these possibilities.¹²⁹ Thus, the problem here is not the semantic clarity of the treaty, but priorities and, most importantly, some means for determining compliance with requirements of the law.

Perhaps the answer to these questions is that the State may adopt any of these options, including devoting "the maximum available resources" to a tertiary level hospital to engage in newborn screening, to the exclusion of any other means for implementing

¹²⁶ This task is performed by a new committee of independent experts operating under ECOSOC. See Alston, *Out of the Abyss: The Challenges Confronting the New U.N. Committee on Economic, Social and Cultural Rights*, 9 HUMAN RIGHTS QUARTERLY 332 (1987).

¹²⁷ It is clear that "[a] failure by a State Party to comply with an obligation contained in the Covenant is, under international law, a violation of the Covenant." *The Limburg Principles on the Implementation of the International Covenant on Economic, Social and Cultural Rights*, Principle 70, reprinted in 9 HUMAN RIGHTS QUARTERLY 122, 131 (1987) [hereinafter *Limburg Principles*]. It is not clear that the new independent committee of experts, as it operates as an arm of ECOSOC, has authority to declare violations. See *id.* at 133, Principle 83. Principle 83 provides that, "[t]he Committee has been entrusted with assisting the Economic and Social Council in the substantive tasks assigned to it by the Covenant. In particular, its role is to consider States parties' reports and to make suggestions and recommendations . . . as to fuller compliance with the Covenant by States parties." *Id.*

¹²⁸ *International Covenant on Economic, Social and Cultural Rights*, *supra* note 103, at Art. 12(2); see also Grant, *Introduction*, to UNICEF, *supra* note 3, at 3.

¹²⁹ See *International Covenant on Economic, Social and Cultural Rights*, *supra* note 103, at art. 12.

the right to health, even perhaps to the exclusion of all of the Economic Covenant's other rights. Such a policy would certainly protect the right of health (and life) of those neonates with serious metabolic disorders, but it would send other protected health rights begging. At this point the WHO Primary Health Care program,¹³⁰ with its emphasis on reaching the population as a whole,¹³¹ would likely counsel against such an unbalanced allocation of resources. However, the WHO advice hardly amounts to a binding rule of international law, and stubborn pursuit of a policy contrary to the views of international health care experts is not legally forbidden.

These problems of finding priorities among the rights in the Economic Covenant are compounded when consideration is given to rights protected by other human rights treaties that also require resources for their implementation.¹³² From a human rights perspective, the outcome of this competition always produces meritorious winners. But insofar as economic support for rights competes for resources with public needs that are not human-rights enforcing, the outcome may be much less desirable. The same funds that could initiate a newborn screening program, for example, could also pave many miles of highway, subsidize a national airline, purchase advanced missiles, or clean up some of the environment. In the context of competition of this sort, it is far from clear what a "maximum of its available resources" means, and what the role of international monitoring should be.

These pivotal questions did concern the drafters of the Economic Covenant.¹³³ After reviewing discussions of these issues that took place during the process of drafting the Economic Covenant in the United Nations Human Rights Commission, Alston and

¹³⁰ *Primary Health Care*, *supra* note 81.

¹³¹ "The existing gross inequality in the health status of people is of common concern to all countries and must be drastically reduced. An equitable distribution of health resources, both among countries and within countries, leading to universal accessibility to primary health care and its supporting services, is therefore fundamental to the Strategy." WHO GLOBAL STRATEGY, *supra* note 81, at 34.

¹³²

[T]he reality is that the full realization of civil and political rights is heavily dependent both on the availability of resources and the development of the necessary societal structures. The suggestion that realization of civil and political rights requires only abstention on the part of the state and can be achieved without significant expenditure is patently at odds with reality.

Alston & Quinn, *supra* note 124, at 172.

¹³³ *See id.* at 177-81.

Quinn conclude that, while a State does have great discretion in allocating its resources and is entitled to claim that these resources are insufficient for realization of the Economic Covenant's rights, "[i]n the final resort, however, such a plea remains open to some sort of objective scrutiny by the body entrusted with responsibility for supervising States' compliance with their obligations under the Covenant."¹³⁴

Despite this need for an "objective scrutiny" in order to maintain the integrity of a system of legal obligations, the reports currently being submitted to the monitoring body by States Parties to the Economic Covenant appear to provide little or no information needed for exercising the scrutiny. This leaves the committee of experts no basis for objectively determining whether there are resources available. Perhaps the absence of data relating to resources in the reports of Third World nations such as Tunisia,¹³⁵ Colombia,¹³⁶ and Cameroon¹³⁷ is understandable on the basis of an unspoken assumption that they lack resources. But the same can hardly be said of States Parties from the developed world whose reports are similarly unforthcoming on the question of resources.

The French report, for example, does not address how and why resources have been allocated for covenant purposes among the various facets under the right to health, or among other specific rights protected by the Economic Covenant, or by other human rights treaties to which France is a party. The report also fails to address the decision-making process for identifying the resources that have been set aside to fulfill non-rights obligations taken on by France. The 1986 French report to the committee of independent experts makes no plea of resource scarcity and merely informs the committee that it has devoted a certain proportion of its wealth (8%) to the right to health.¹³⁸ Whether this proportion is within France's

¹³⁴ *Id.* at 181.

¹³⁵ *Implementation of the International Covenant on Economic, Social and Cultural Rights; Initial Reports Submitted by States Parties to the Covenant, in Accordance with Council Resolution 1988 (LX), Concerning Rights Covered by Articles 10-12: Tunisia*, U.N. Doc. E/1986/3/Add.9 (1987).

¹³⁶ *Implementation of the International Covenant on Economic, Social and Cultural Rights; Second Periodic Reports Submitted by States Parties to the Covenant Concerning Rights Covered by Articles 10 to 12, in Accordance with the Second Stage of the Programme Established by the Economic and Social Council in its Resolution 1988 (LX): Colombia*, U.N. Doc. E/1986/4/Add.25 (1988).

¹³⁷ *Implementation of the International Covenant on Economic, Social and Cultural Rights; Initial Reports Submitted by States Parties to the Covenant, in Accordance with Council Resolution 1988 (LX), Concerning Rights Covered by Articles 10-12: Cameroon*, U.N. Doc. E/1986/3/Add.8 (1987).

¹³⁸ "The financial resources available for health represent about 8 per cent of the gross

margin of discretion cannot be ascertained as there are no data on unmet health needs (including newborn screening), what it would cost to meet them, and why funds for this purpose have not been made available. The Dutch report also notes the percentage of its wealth devoted to health (8.6%) but gives the committee no basis for determining the adequacy of this commitment in the context of unmet needs and potential resources.¹³⁹

The United Kingdom report¹⁴⁰ is similarly useless for monitoring purposes. The closest it comes to documenting what resources it considers to be available is the declaration that spending on the health service has risen by over twenty percent in real terms between 1978/79 and 1984/85.¹⁴¹ The report fails to address which health needs have been favored by this rise and which neglected, and why, in light of unmet health needs. It only assumes that a twenty percent increase is deemed to constitute a commitment of the maximum available resources. Thus, the monitoring committee of experts is left unable to determine compliance. Furthermore, when each State Party appears before this committee, there is no questioning on the issue of what resources are available and why.¹⁴² Such matters could sensibly be presented by government budget experts and evaluated by a committee that would include an expert in public accounting, but this is not the kind of technical skill or discourse normally found at human rights meetings.

France, the Netherlands, and the United Kingdom all screen neonates for PKU and congenital hypothyroidism,¹⁴³ but not for

national product, they amounted to about F5,900 per person, or a total of F316.6 billion, in 1986." *Implementation of the International Covenant on Economic, Social and Cultural Rights; Initial Reports Submitted by States Parties to the Covenant, in Accordance with Council Resolution 1988 (LX), Concerning Rights Covered by Articles 10-12: France*, at 50, U.N. Doc. E/1986/3/Add.110 (1987).

¹³⁹ *Implementation of the International Covenant on Economic, Social and Cultural Rights; Second Periodic Reports Submitted by States Parties to the Covenant, Concerning Rights Covered by Articles 10 to 12, in Accordance with the Second Stage of the Programme Established by Economic and Social Council Resolution 1988 (LX): Netherlands*, at 226, U.N. Doc. E/1986/4/Add.24 (1987).

¹⁴⁰ *Implementation of the International Covenant on Economic, Social and Cultural Rights; Second Periodic Reports Submitted by States Parties to the Covenant, Concerning Rights Covered by Articles 10 to 12, in Accordance with the Second Stage of the Programme Established by Economic and Social Council Resolution 1988 (LX): United Kingdom of Great Britain and Northern Ireland*, U.N. Doc. E/1986/4/Add.23 (1987) [hereinafter *United Kingdom Report*].

¹⁴¹ *Id.* at 82.

¹⁴² See, e.g., *Committee on Economic, Social and Cultural Rights; Report on the Third Session*, Feb. 6-24, 1989, U.N. Doc. E/C.12/1989/5, at 52-59 (questions and replies relating to the *United Kingdom Report*, *supra* note 140).

¹⁴³ *International Screening Status Report*, *supra* note 12. These two disorders are the minimum recommended for inclusion in screening programs by the American Academy of Pediatrics and the American College of Obstetricians and Gynecologists. See AMERICAN ACAD-

any of the other serious disorders that can be included in a comprehensive program.¹⁴⁴ Do the newborns in these three countries who may die or suffer from undetected MSUD, homocystinuria, or galactosemia have a currently guaranteed international right under the Economic Covenant to be protected from those disorders? Do the newborns in these countries receive screening for PKU and for congenital hypothyroidism as a matter of right? Are these two screening programs mandated by the Economic Covenant's requirement that States Parties take the steps necessary to reduce infant mortality and to provide for the healthy development of children, or are children's rights at the international level indistinguishable from child welfare and public charity?

If Article 12 of the Economic Covenant does require screening, it would seem that the requirement is imposed on *all* States Parties, rich and poor alike. No distinctions based on resources are to be found in Article 12 of the Economic Covenant. That is left to Article 2. It should be noted, however, that Article 2 is a two-sided coin. The French delegate in the group engaged in drafting the Economic Covenant observed that "[t]he progressive realization of the rights set forth in the Covenant should depend entirely on the resources available to a State, and should not be invoked by States as grounds for failing to implement a right when resources were available."¹⁴⁵ In other words, Article 2 mandates that when the resources are present there is a duty to implement the rights such as those in Article 12. Article 2 has a differential impact not only at some particular point in time, excusing the poor countries and obliging the wealthy ones, but also over time, imposing duties on States Parties as their resources grow, and relieving States Parties of duties should their resources be negatively affected by deteriorating economic conditions.¹⁴⁶ There is thus a dynamic quality to

EMY OF PEDIATRICS & AMERICAN COLLEGE OF OBSTETRICIANS AND GYNECOLOGISTS, GUIDELINES FOR PERINATAL CARE 90 (2d ed. 1988).

¹⁴⁴ See AMERICAN ACADEMY OF PEDIATRICS & AMERICAN COLLEGE OF OBSTETRICIANS AND GYNECOLOGISTS, *supra* note 143, at 90-93.

¹⁴⁵ Quoted in Alston & Quinn, *supra* note 124, at 174.

¹⁴⁶ UNICEF has examined the relationship between deteriorating economic conditions and the welfare of children in a report that includes the observation that,

[a]ccording to the central theme of the development literature of the late 1960s to the early 1980s, poverty, malnutrition and high infant and overall mortality primarily result from structural (as opposed to cyclical) causes, and progress in human welfare depends more on the pattern rather than the rate of economic growth. In many instances, domestic factors such as unequal land distribution, insecure and inequitable tenancy agreements, a skewed distribution of income, misuse of public finance

the rights and duties in the covenant introduced by Article 2 that makes it pointless to ask in the abstract what the meaning is of any particular programmatic right, including whether Article 12 means that newborn screening is a legal requirement. But questions of meaning that are rooted to particular times and places are far from pointless.

Concerning PKU and congenital hypothyroidism, there is little room to dispute that the resources for this screening are available in France, the Netherlands, and the United Kingdom, as well as in other States Parties where these tests are being conducted.¹⁴⁷ Since newborn screening clearly comes within the broad general language of Article 12, it can be concluded that, at the present time in these States Parties, PKU and hypothyroidism screening is a human right.

At this point no one seems to know whether there are resources available for additional screening of newborns in France, the Netherlands, or the United Kingdom. These governments act as if they have determined that resources are *not* available for MSUD, galactosemia, and other disorders, but there appears to have been no objective scrutiny of these decisions, and it is far from clear that the analysis entailed in the scrutiny would find it acceptable that a broader screening program cannot be afforded. It is at least theoretically possible that the failure to broaden the existing screening program is a denial of the human rights of afflicted newborns. The reports submitted to the ECOSOC committee of experts do not acknowledge that governmental decisions of this sort have been made, still less do they contain any relevant data or policy justifying those decisions for the committee to review. Whether the resource decisions that have been reached can withstand objective scrutiny is thus unknown.

The same must be said concerning newborn screening in developing countries such as Tunisia, Morocco, and Cameroon. The

and the socio-cultural marginalization of entire sections of the population on religious, class and ethnic grounds have a far greater influence on standards of living than the growth—or the decline—of the overall economy.

Cornia, *A Summary and Interpretation of the Evidence*, in UNICEF, *THE IMPACT OF WORLD RECESSION ON CHILDREN* 211 (1984). This report, however, does not appear to recognize that there is a role for international law in coping with some of these structural causes. There is a similar unexplored role of assuring equity and fairness in the distribution of resources arising from the worldwide increases in health care costs that are pressing all countries to implement some form of rationing.

¹⁴⁷ These other countries include: Australia, Brazil, Costa Rica, Greece, and Sweden. See *International Screening Status Report*, *supra* note 12.

policy of these governments to refrain from all newborn screening is not articulated in their reports, and there is no way of telling whether principles of objective scrutiny would verify that these and other States Parties to the Economic Covenant from the developing world lack the resources needed for any kind of newborn screening. But if Third World children are to have rights equal to those children in the developed world, there must be an objective review of all political judgments that resources are not available. As noted by Mexican researchers, newborn screening "depends therefore both on financial support and on health policies, both of which are in turn related to political decisions by the current health authorities."¹⁴⁸ There are many indications that medical scientists outside the developed world are prepared to institute routine newborn screening.¹⁴⁹ This makes it possible that an international monitoring agency, if presented with relevant data, might objectively conclude that a developing nation is devoting an inordinate amount of its resources to its defense establishment, to subsidizing its national airline, to overcompensating its public officials, or to sending some of its children abroad for education, and thereby not committing a maximum of its available resources to a right to health that includes newborn screening.¹⁵⁰ This conclusion could be more easily reached if the disorders that can benefit from screening, such as hemoglobinopathies, occur with great frequency in a particular State Party.¹⁵¹ It is certain that the phenomena of waste, inefficiency, corruption,¹⁵² and indefensible priorities are not exclusively the

¹⁴⁸ Rodriguez, Martinez, & Velaquez, *Neonatal Metabolic Screening in Developing Countries: The Case of Mexico*, in *ADVANCES IN NEONATAL SCREENING*, *supra* note 24, at 461, 466.

¹⁴⁹ See, e.g., Chen, *supra* note 24; Al-Awadi, Teebi, Farag, & Naguib, *Inherited Metabolic Disease in Kuwait: The Need for a Nation-wide Neonatal Screening* in *ADVANCES IN NEONATAL SCREENING*, *supra* note 24, at 479, 480; Al-Awamy, *supra* note 38; Kulkarni & Jekeme, *Cord Blood Screening for Haemoglobinopathies in Northern Nigeria*, 80 *ANNALS TROPICAL MED. & PARASITOLOGY* 549 (1986); Pandav & Kochupillai, *Organisation and Implementation of Neonatal Hypothyroid Screening Programme in India—A Primary Health Care Approach*, 52 *INDIAN J. PEDIATRICS* 223 (1985).

¹⁵⁰ For a detailed analysis of the effects of the increase in developing countries' share of world military spending on social welfare in these countries, see M.D. OLPIN, *MILITARIZATION, INTERNAL REPRESSION AND SOCIAL WELFARE IN THE THIRD WORLD* (1986).

¹⁵¹ In some countries, the resource scarcity may relate to gathering the statistics necessary to determine prevalence accurately.

¹⁵² See, e.g., Hogg, *Mobutu Steals a March on Critics*, *The Sunday Times* (London), Apr. 29, 1990, (Overseas News section). This article reported on the lifestyle of President Mobutu Sese Seko of Zaire:

Crystal chandeliers and television sets decorate virtually every room, and regular flights from Belgium, Zaire's former colonial master, ensure plentiful supplies of the president's favorite wine. Mobutu can choose from more than 50 Mercedes cars,

province of industrial world governments, and the achievement of equality in this context can be served only by using the reporting mechanism under the Economic Covenant to require *all* States Parties to address the availability-of-resources issue.¹⁵³

We conclude from this examination of the Economic Covenant that although it represents a major advance by introducing children's health as a matter protected by international law, the process for ensuring that the rights thus created are effectively implemented has been seriously flawed.¹⁵⁴ Having noted the problems of determining whether newborn screening is included in the children's right to health under the Economic Covenant, an analysis of that issue as it is presented in the Convention can now be undertaken.

even though the appalling state of the roads means he is more likely to use his luxury yacht on the river Zaire or choose from his fleet of private planes.

... His ownership of foreign property, including at least 11 chateaux in Belgium, a building on the Avenue Foch in Paris, a residence in Nice, a villa in Switzerland and a 16th century castle in Spain, is legendary.

Id.

¹⁵³ The Executive Director of UNICEF has emphasized the inequality issue in the context of resource allocation:

It is time for leaders to pause and take stock, not simply of their budgets, but of human needs and the current allocation of resources to meet them. It is not enough to say, "Our resources are meagre, our needs too great." In every area of human need it is now possible to make significant progress through relatively modest shifts in resources which are very often weighted against the poorest and neediest groups in favour of those who are better-off.

In health, the hospitals, doctors and medical technologies, which reach 15 per cent of the population, often claim 60 per cent to 80 per cent of the budget.

Grant, *supra* note 128, at 4.

UNICEF has reported cognate inequalities in education:

Bangladesh ranks 107th in literacy among 131 countries, with a rate of 33% for those 15 years and older Although 80% of the population lives in rural areas, 70% of the education investment goes to urban areas, most to higher education In its most recent five-year plan, Bangladesh stated a goal of reaching 70% of its primary school-age children with education by the year 1990. Budget appropriations, however, make the implementation of this goal unlikely.

UNICEF, *ASSIGNMENT CHILDREN, THE BRAC NON-FORMAL PRIMARY EDUCATION PROGRAMME IN BANGLADESH* 7 (1989) [hereinafter *ASSIGNMENT CHILDREN*].

Article 28 of the Convention, *supra* note 4, states: "1. States Parties recognize the right of the child to education, and with a view to achieving this right progressively and on the basis of equal opportunity, they shall, in particular: (a) Make primary education compulsory and available free to all." The UNICEF evaluation of the BRAC program indicates that children are charged unauthorized fees. *ASSIGNMENT CHILDREN, supra*, at 30.

¹⁵⁴ The proposals for utilizing the reporting procedures under the Convention (*see infra* pp. 00-00) are not in conflict with recently formulated suggestions for improving implementation of the Economic Covenant set out in Alston, *supra* note 136, at 350-79.

V. NEWBORN SCREENING AND THE RIGHT TO HEALTH UNDER
ARTICLE 24 OF THE CONVENTION¹⁵⁵

A. *The Contingent Nature of Health Rights Under the Convention*

To understand the impact of Article 24, it must first be appreciated that Article 4 of the Convention contains an availability-of-resources provision similar to Article 2 of the Economic Covenant.¹⁵⁶ Article 4 provides:

States Parties shall undertake all appropriate legislative, administrative, and other measures for the implementation of the rights recognized in the present Convention. With regard to economic, social and cultural rights, States Parties shall undertake such measures to the maximum extent of their available resources and, where needed, within the framework of international cooperation.¹⁵⁷

There are a number of differences between this formulation and the terminology of Article 2(1) of the Economic Covenant. There is, for example, no reference to "progressively" in this general provision of the Convention.¹⁵⁸ But if the Convention requires implementation as resources become available, then the idea of progressive achievement is built in. The absence of a requirement for progressive achievement also makes it easier to accept the view that rights do not become "locked in" when a State Party experiences a loss of resources. In some ways, however, this Convention provision is more complicated than its counterpart in the Economic Covenant.

Applicability of the reference to resources in Article 4 of the Convention depends on whether the particular right in question is deemed to be an economic, social, or cultural right on the one hand, or another kind of right—probably a civil right—on the other.¹⁵⁹ In the former case, a lack of resources would limit the State's obligation to undertake appropriate measures of implementation, whereas in regard to the latter rights, the availability of resources does not limit the duty to take all appropriate implementing measures. Perhaps the term "appropriate" in Article 4 functions implicitly to limit the

¹⁵⁵ *Convention, supra* note 4, at art. 24.

¹⁵⁶ *See International Covenant on Economic, Social and Cultural Rights, supra* note 103, at art. 2(1).

¹⁵⁷ *Convention, supra* note 4, at art. 4.

¹⁵⁸ The right to education that is recognized in the Convention, however, is expressly made subject to progressive achievement. *Id.* at art. 28(1).

¹⁵⁹ The Convention does not otherwise identify the class or nature of the rights it provides. *Id.*

duty to implement civil rights when resources are scarce in exactly the same way that economic, social, and cultural rights are explicitly limited by the "availability of resources" language. But that would mean that the drafters of the Convention said the same thing with entirely different words, and all in the same article, an interpretive approach not normally adopted. Nor would it be permissible to take "appropriate" as meaning "any steps which appeal to the State Party," since discretion of that breadth leaves virtually no room for a legal duty. On the other hand, the duty to implement that is articulated in Article 4 is less than would be imposed if the term "necessary" had been employed instead of "appropriate." Seen as imposing a duty that is more strict than complete State discretion and less strict than one requiring all that is necessary, "appropriate" recognizes a gray range of discretion in making a good faith effort to implement the Convention's rights. Whether the permissible range of discretion has been exceeded in any particular case must be for the judgment of the international monitoring agency and the other States Parties.¹⁶⁰ The significance of the reference to what is appropriate depends on whether Article 4 bears the same message as its predecessor in the Economic Covenant and on the question of the particular rights to which the resources limitation applies.

It appears from the *travaux préparatoires* of the Convention that Article 4 should be interpreted similarly to Article 2 of the Economic Covenant. The original draft of the Convention submitted to the United Nations Human Rights Commission by Poland in 1978¹⁶¹ evoked major criticism from some countries that its vague language was more appropriate for a Declaration than for a legally binding instrument.¹⁶² Others stressed the need to examine existing United

¹⁶⁰ "In accordance with international law each State party to the Covenant has the right to express the view that another State party is not complying with its obligations under the Covenant and to bring this to the attention of that State party." *Limburg Principles*, *supra* note 127.

¹⁶¹ U.N. Doc. E/CN.4/L.1366, at 2 (1978).

¹⁶² This position was succinctly put in the response by Sweden:

In this work it is natural to seek inspiration from the Declaration of the Rights of the Child Consequently the provisions of that Declaration could be a starting-point when drafting a new convention. It would not be desirable, however, simply to include the text of the Declaration in a convention, since the two instruments are of a different legal character and provisions which are appropriate in a Declaration will not always be well suited to constitute legally binding rules. The 1959 Declaration contains certain general statements which do not have their proper place in the operative part of a convention which, being an agreement between States, should lay down concrete, mutual obligations.

Question of Convention, *supra* note 82, at 16.

Nations human rights instruments in the drafting of a convention for children. The Cyprus delegation, in particular, proposed incorporating a provision in the draft that would recognize the economic capabilities of States Parties, citing Article 2 of the Economic Covenant as a model.¹⁶³

The revised draft presented by Poland the next year did include a provision addressing the nature of the obligations undertaken by States Parties, but without reference to the economic capability distinctions that had been suggested by Cyprus.¹⁶⁴ Proposals similar to the Polish revision were made by Norway and Australia,¹⁶⁵ but no action was taken on the resources issue until 1981, when the Working Group, the Convention's drafting committee, had before it a United States proposal that for the first time picked up the resources idea of the Economic Covenant. This provided that: "Each State Party to the present Convention shall take steps, in accordance with its constitutional processes and *its available resources*, with a view to achieving the full realization of the rights recognized in the present Convention by all appropriate means, including particularly the adoption of legislative or administrative measures."¹⁶⁶ This provision was the third paragraph of a proposed article that also dealt with rights of alien children and with protection against discrimination. As part of a compromise reached on these issues, the third paragraph was dropped, but was later brought to the attention of the Working Group as an alternative to the Polish, Norwegian, and Australian formulations then being discussed.¹⁶⁷ A Brazilian rephrasing that included the "available resources" language was then adopted,¹⁶⁸ and the final version of Article 4, with the addition of the distinction between different kinds of rights, was accepted in 1989.¹⁶⁹

It thus appears that, as has been suggested in regard to measures under the Economic Covenant, a State Party is legally obli-

¹⁶³ *Id.* at 8.

¹⁶⁴ The revised Polish draft included an Article 4, which read in part: "The States Parties to the present Convention shall undertake appropriate measures individually and within the framework of international co-operation, particularly in the areas of economy, health and education for the implementation of the rights recognized in this Convention." U.N. Doc. E/CN.4/L.1575, reprinted in *Report of the Working Group on a Draft Convention on the Rights of the Child*, at 7, U.N. Doc. E/CN.4/L.1575, (1981).

¹⁶⁵ *Id.*

¹⁶⁶ *Id.* at 8 (emphasis added).

¹⁶⁷ *Id.* at 10.

¹⁶⁸ *Id.*

¹⁶⁹ *Convention*, *supra* note 4, at art. 4.

gated to provide appropriate measures which it can afford for the implementation of economic, social, and cultural rights in the Convention. Making the distinction between the two classes of rights, however, is complicated in the present context because Article 24 is not the only part of the Convention addressing the health of children. Specifically, Article 6 provides that States Parties: "1. . . . recognize that every child has the inherent right to life," and "2. . . . shall ensure to the maximum extent possible the survival and development of the child."¹⁷⁰ A duty to engage in newborn screening is within the general language of the Article 6(2) obligation to "ensure to the maximum extent possible the survival and development of the child." If it is also recognized that the disorders within screening programs are potent threats to the child's "inherent right to life," then screening can also be seen as included within Article 6(1). The resource condition of Article 4 would not be applicable if these Article 6 civil rights were designated "civil" rights rather than economic, social, or cultural rights. Whether a State Party could afford to implement Article 6 civil rights would then be irrelevant. Such an assertion would be supported by analogy to the inherent right to life in Article 6(1) of the International Covenant on Civil and Political Rights,¹⁷¹ which is similarly unconditional by virtue of its being expressly not subject to derogation.¹⁷² Although there is no authoritative definition of what is civil and what is economic, social, and cultural, conceptual similarity of particular Convention rights to rights in one or the other of the two 1976 covenants is one possible source of classification. This indicates that Article 6 of the Convention is a civil right.

There are, however, textual reasons for rejecting the interpretation that the right to health implied in Article 6 is not conditioned by the resources issue. As to the inherent right to life, States Parties are obliged only to "recognize" this right, a relatively weak undertaking that does not imply the need to take any particular or specific measures, and may therefore require doing what is possible in the context of available resources.¹⁷³ Moreover, whereas the right to

¹⁷⁰ *Id.* at art. 6.

¹⁷¹ *Supra* note 92, at art. 6(1).

¹⁷² *Id.* at art. 4(2).

¹⁷³ Concerning "recognized" rights in the Economic Covenant, Alston and Quinn have noted:

Where the texts of the various rights are silent on the concrete steps to be taken by states in fulfillment of their obligations with regard to the rights "recognized" the relevant obligations can best be understood as hybrids between obligations of result

survival and development in Article 6(2) is the object of a duty to "ensure," and not merely to "recognize," States Parties must ensure the right only "to the maximum extent possible," implying that there is both a gray area of discretion and that the duty is similarly subject to what is possible in the context of available resources. Nonetheless, it may seem strange that rights as fundamental as those expressed in Article 6 should be weak and conditional, especially in light of the obvious effort expressed in Article 4 to make civil rights non-contingent. But it is precisely this effort that creates the confusion, since it represents a failure to acknowledge that protection of civil and political rights commonly also consumes resources.¹⁷⁴

B. *Monitoring Implementation Under the Convention*

Thus, whether newborn screening is seen as implied by the Article 6 rights to life, survival, and development or as within the Article 24 social duty to diminish infant mortality and "[t]o ensure the provision of necessary medical assistance and health care,"¹⁷⁵ it would be subject to the availability-of-resources provision of the Convention. As is the case with the Economic Covenant, the need to maintain the integrity of the Convention as a system of legal obligations dictates that States Parties' decisions concerning this availability of resources must be subject to an *objective scrutiny*. Therefore, the WHO position that "only economically developed countries can contemplate nationwide [screening] programmes"¹⁷⁶ may not always be a sound one, since the committee of experts set up under the Convention cannot fail to require of States Parties in the developing world the same disclosure-of-resources allocation that is required from the more affluent States Parties. The necessary experience and information for making this disclosure may already

and obligations of conduct. They are obligations of result in the sense that states must match their performance with their objective capabilities. They are loose obligations of conduct in the sense that states are obliged to take active, though largely unspecified, steps toward their satisfaction.

Alston & Quinn, *supra* note 124, at 185.

¹⁷⁴ See *id.* at 173-74. At the drafting session that considered the text of what became Article 6, the chairman of the Working Group compared the right to life then being debated with the right to life in Article 6 of the Covenant on Civil and Political Rights (*supra* note 92) noting that the latter was primarily negative while the right to life that belonged in the Convention "should be positive and should take into account economic, social and cultural conditions." *Question of A Convention on the Rights of the Child; Report of the Working Group on a Draft Convention on the Rights of the Child*, at 7, U.N. Doc. E/CN.4/1988/28 (1988).

¹⁷⁵ *Convention*, *supra* note 4, at art. 24(2)(b).

¹⁷⁶ HEALTH ASPECTS, *supra* note 108; see *id.* and accompanying text.

be available in some of the developing countries.¹⁷⁷ As to all States Parties, administration of the Convention's reporting requirements should profit significantly from recognition of the inadequate nature of the reports currently being submitted under the Economic Covenant. Scrutiny requires a focus on the question of whether a State Party, whatever its economic development, can objectively afford to allocate resources for newborn screening. The committee will be in a position to employ the necessary accounting and budgeting expertise by virtue of the power it has under Article 45(a) to "invite . . . competent bodies as it may consider appropriate to provide expert advice on the implementation of the Convention in areas falling within the scope of their respective mandates."¹⁷⁸

The committee's evaluation of State Party implementation will, of necessity, be highly individualistic, taking into account many factors such as the absolute wealth of the nation, the need for distributing its resources among other rights-related and rights-unrelated programs, a cost/benefit analysis of the screening program,¹⁷⁹ current resource-allocation patterns, the availability of in-

¹⁷⁷ For example, it is reported that in Costa Rica [p]rematurity and other birth defects are the current leading causes of infant morbidity and mortality. Resources for the detection, diagnosis and treatment of these problems, including inborn errors of metabolism, are insufficient; in fact, the general and economical development of the country is well behind the partial improvements in public health.

To meet the formidable challenge that this "new pathology" represents, the installment of a nationwide neonatal screening program for inborn errors of metabolism seems imperative, not only as an efficient strategy to counteract the immediate impact of these diseases in terms of mental retardation and/or other disabilities, but also to serve as a basis for a broader program for the prevention of other genetic or partially genetic diseases.

. . . In summary, only PKU and MSUD have been included so far . . . Congenital hypothyroidism and galactosemia have been considered, but not included yet because of lack of budget and relatively complicated screening tests. MSUD was included, because of an apparent high frequency of this disease in Costa Rica.

De Cespedes, *Problems in Implementing Newborn Screening in Costa Rica*, in *ADVANCES IN NEONATAL SCREENING*, *supra* note 24, at 475.

¹⁷⁸ *Convention*, *supra* note 4, at art. 45(a). The committee may also invite the assistance of any United Nations agencies possessing expertise in the analysis of national expenditure patterns by virtue of the appropriate additional power in this same article. Article 43(11) requires the Secretary General to provide the staffing that is necessary "for the effective performance of the functions of the Committee." *Id.* at art. 43(11) Dynamic and creative use of the resources thus made available to the committee can make it a potent force in bringing about disclosure of budgeting data relating to children's health and the development of international standards for evaluating its legal significance.

¹⁷⁹ See, e.g., Carrasco, et al., *Cost Benefit Analysis of the Mexican Neonatal Screening Program for Inborn Errors of Metabolism* in *ADVANCES IN NEONATAL SCREENING*, *supra* note 24, at 447 (reporting a net saving of \$3,494). Compare this conclusion with the proposal that routine

ternational assistance, and other policy choices.¹⁸⁰ This is a highly complex undertaking, and developing the principles and techniques of analysis will require the attention of a variety of experts.

Clearly, however, some mechanism is required to bring issues, such as the availability of newborn screening, to the attention of the committee. It cannot be expected that it will, *sua sponte*, raise such issues with reporting States Parties either at oral questioning on the reports or in requests for additional information;¹⁸¹ the committee cannot be expected to have a familiarity with such health issues in its own knowledge. Nor is it likely that, in its report of implementation under Article 24, a State Party will itself address the question of why it is not engaging in every possible effort to reduce infant mortality. As a practical matter, the burden of introducing the issue of newborn screening, rather, lies with the "other competent bodies" that do possess expertise in such matters and from whom the committee is authorized to invite expert advice.¹⁸²

The centrality of "other competent bodies" in the implementation process derives from the nature of the terminology employed in Article 24 and in the body of the Convention as a whole. It will be recalled that the language of the Declaration of the Rights of the Child was rejected for the Convention on the grounds that

prenatal screening and immunization of mothers in the United States, designed to reduce the transmission rate to neonates of hepatitis B, which may be as high as 90%, would produce a net annual savings of more than \$105 million. Arevalo & Washington, *Cost-Effectiveness of Prenatal Screening and Immunization for Hepatitis B Virus*, 259 J. AM. MED. A. 365 (1988).

¹⁸⁰

Availability of a test is insufficient reason for instituting a public screening program. Some of the chemical disorders which are detected are not associated with any disease state. For others, the relation is uncertain and further study is needed. Also, many tests require further validation. As a minimum condition newborn screening should meet at least one of the following criteria before it is offered as a routine service: (1) Affected subjects who are discovered will benefit, as in the case of PKU, from the early institution of therapy; (2) affected subjects and their families will be apprised of hazardous situations which should be avoided; (3) the families of affected subjects discovered to have genetic disorders can be counseled about risks of recurrence.

N. HOLTZMAN, *supra* note 19, at 5. Accordingly, the issue of whether resources are available should, in the case of possible PKU screening, take account of such things as the cost of food that is free of phenylalanine and of counseling services. Cf. Holtzman, *Routine Screening of Newborns for Cystic Fibrosis: Not Yet*, 73 PEDIATRICS 98 (1984); Colten, *Screening for Cystic Fibrosis, Public Policy and Personal Choices*, 322 NEW ENG. J. MED. 328 (1990) (still unclear whether newborn screening is warranted).

¹⁸¹ "The Committee may request from States Parties further information relevant to the implementation of the Convention." *Convention, supra* note 4, at art. 44(4).

¹⁸² *Id.* at art. 45(a).

greater specificity was needed in the Convention.¹⁸³ The Swedish call for “concrete, mutual obligations” has succeeded in several parts of the Convention that impose clear and specific duties.¹⁸⁴ In addition, Article 24 is far more specific in protecting children’s health than is Article 12 of the Economic Covenant. But it is the *relative* specificity of Article 24 that must be emphasized. The duties it creates are still cast in broad and general language—for example, diminishing infant and child mortality and providing necessary medical assistance—that covers every conceivable means for saving children’s lives and for employing every technique of modern medical science. On their face these provisions still closely resemble the manifesto statements in United Nations declarations. They also resemble the sweeping terms of the American Constitution such as due process and equal protection.¹⁸⁵ It would, in fact, be accurate to see a right to “necessary medical assistance” as the conceptual equivalent of an international law guarantee of due process in health care and the “competent bodies” as standing in the position of private parties making claims of a class action nature for rights under the Convention, such as newborn screening. This analogy to the litigation process for establishing constitutional rights is a very imperfect one, but that process nonetheless serves as a useful model for understanding how newborn screening can be established as a right under the Convention.

For this purpose, assume that the population of a State Party includes substantial numbers of persons who are vulnerable to a particular disorder that can be effectively screened, sickle cell disease in blacks for example, but that no such screening is carried out. A family who discovers that its child has the disease, knowing that health rights are protected under the Convention,¹⁸⁶ might bring the failure to screen to the attention of an international organization such as Save the Children or Defense for Children International, or to a domestic organization such as The National Children’s Bureau in the United Kingdom or the American Academy of Pediatrics, or to any body with experience in presenting similar material to judicial, legislative, and administrative authori-

¹⁸³ *Question of Convention*, *supra* note 82.

¹⁸⁴ *See, e.g., Convention*, *supra* note 4, at art. 37(a) (capital punishment forbidden “for offences committed by persons below eighteen years of age”).

¹⁸⁵ U.S. CONST. amend. XIV § 1.

¹⁸⁶ *See Convention*, *supra* note 4, at art. 42 (“States Parties undertake to make the principles and provisions of the Convention widely known, by appropriate and active means, to adults and children alike.”).

ties.¹⁸⁷ More likely, these bodies might decide on their own that newborn screening for sickle cell disease should be part of the nation's preventive health program. Ordinarily, they would then present the case for establishing the screening program to the appropriate government agencies of the State Party. If this proposal is not accepted, they might then request that the substance of the request and the government's response be included in the next report to the Committee on the Rights of the Child relating to implementation of Article 24. Whether or not this latter request succeeds, the body could "appeal" the government's refusal to undertake the screening by submitting its full case for screening to the committee. This can be accomplished either by informally presenting its "brief" to a member of the committee in the expectation that the committee will formally invite the body to provide expert advice or, if it has already established its expertise with the committee, by responding to such an invitation that the committee might routinely issue. The committee may even invite the body to make an oral presentation of its case when the State Party's report is being considered.¹⁸⁸

The crux of this technical assistance to be rendered to the committee is that the scientific and epidemiological facts pertaining to the State Party, considered in the light of available resources, makes failure to screen for sickle cell disease a matter of concern for the committee when it reviews the State Party's implementation of Article 24.¹⁸⁹ It should be noted that this is not a view that is pressed on behalf of a family or child who might have initiated the matter, since there is no right of individual petition under the Convention. In keeping with the programmatic nature of many of

¹⁸⁷ See, e.g., AMERICAN ACADEMY OF PEDIATRICS, GOVERNMENT ACTIVITIES REPORT 1 (May 1989) ("The Academy has furthered its goal of achieving universal access to health care for all pregnant women and children by initiating the introduction of a congressional resolution entitled 'Health of America's Children.'"). Article 45 does not restrict the "competent bodies" who may be invited to provide advice to the committee to international organizations that have official status with the United Nations as "nongovernmental organizations." Convention, *supra* note 4, at art. 45.

¹⁸⁸ Only the specialized agencies, UNICEF, and other U.N. organs are entitled, without invitation, to be represented at these meetings of the committee. Convention, *supra* note 4, at art. 45(a). But there is nothing to prevent the committee from inviting oral presentations from other sources under its Article 43(8) power to establish rules of procedure. It would be unfortunate if the committee interpreted its mandate so narrowly as to preclude inviting any oral communications from non-State Party sources.

¹⁸⁹ If failure to screen for disorders with potentially fatal consequences, such as PKU, MSUD or galactosemia, were involved, a question of implementation of the Article 6 right to life and survival would be presented as well.

the Convention's rights, it is, rather, a communication calling the committee's attention to programmatic circumstances within the State Party.

The fact that the State Party has a wide, but not open-ended discretion in the matter, especially on the issue of resource availability, does not preclude the committee from deciding that the failure to operate the screening program at issue, in light of demonstrated need and availability of resources, exceeds the scope of legitimate discretion. In that event, the committee can, of course, issue no judgment against the State Party. The Convention expressly limits the power of the committee to the making of "suggestions and general recommendations," not accusations. The whole tenor of the monitoring machinery of the Convention is one of cooperation, not confrontation.¹⁹⁰ As one commentator has noted, "The Convention is not intended to be an instrument for the presentation of complaints."¹⁹¹ But as is acknowledged under the Economic Covenant, the presence of international law necessarily implies the possibility of violation.¹⁹² The committee is responsible for appropriately expressing such disagreement that it may have with the reporting State Party in terms that would make clear the committee's views on the need for a newborn screening program and on the availability of resources for establishing it. Following a review of the State Party's report and of the dialogue concerning it when the report is presented at a meeting of the committee, the conclusion reached may in substance amount to an adoption of the case for newborn screening communicated by the "competent body."

Articulating its opinion concerning violations in this way may be a "suggestion" that goes beyond what the Committee of Independent Experts does under the Economic Covenant, but the difference is justified by the fact that the monitoring undertaken by the experts on the covenant is the responsibility of ECOSOC, on whose behalf they operate, and United Nations agencies do not normally engage in criticisms of member States. Monitoring under the Convention is significantly different in this respect.¹⁹³ Reviewing

¹⁹⁰ "The Committee may make suggestions and general recommendations based on information received pursuant to articles 44 and 45 of the present Convention. Such suggestions and general recommendations shall be transmitted to any State Party concerned and reported to the General Assembly, together with comments, if any, from States Parties." *Convention, supra* note 4, at art. 45(d).

¹⁹¹ Van Bueren, *Comment*, *WORLD'S CHILDREN*, Mar. 1990, at 3.

¹⁹² See *Limburg Principles, supra* note 127.

¹⁹³ In the drafting group, two countries, Poland and Canada, submitted proposals for

the work of the Human Rights Committee, organized under the International Covenant on Civil and Political Rights, leads to a similar conclusion. That committee, a treaty-based body rather than a United Nations agency, is also limited to making general comments, a limitation that nonetheless permits useful clarification of that convention's political and civil rights.¹⁹⁴ But in regard to the economic and social rights that are included in that covenant, general comments contribute virtually nothing to an understanding of what the covenant requires. The Human Rights Committee has, for example, recently concluded that the right of every child under Article 24(1) to "receive from his family, society, and the State, such measures of protection as are required by his status as a minor" means that "every possible economic and social measure should be taken to reduce infant mortality."¹⁹⁵ The programmatic implications of this general comment are impossible to discern. This contribution to international law by the Human Rights Committee hardly progresses beyond the exhortations of General Assembly declarations and provides neither guidance nor persuasion on whether newborn screening is a protected right. The "suggestions and general comments" powers of the Committee on the Rights of the Child must be more extensive than this if the Convention's economic, social, and cultural rights are to contribute to realizing the goal of its founders to produce an international instrument that is more powerful than a declaration.

reporting under the Convention that would have had the reports considered by ECOSOC. Both would have had ECOSOC assisted in this by a Group of Experts (governmental experts under the Polish alternative), creating machinery similar to that which exists under the economic covenant. See *Draft Convention on the Rights of the Child: A Compilation of Proposed Articles and Amendments, and Related Provisions in International Instruments*, at 17, U.N. Doc. E/CN.4/1987/WG.1/WP.2 (1986). A group of non-governmental organizations also submitted an alternative draft article that proposed an independent committee of experts that would not be constrained by being part of the U.N. system. See *id.* at 18. This kind of treaty-based independent committee is now the core of Part II of the Convention.

¹⁹⁴ See, e.g., *Interights*, 4 INTERIGHTS BULL. 41 (1989) (quoting U.N. Doc. CCPR/C/21/Rev. 1/Add. 1 (Nov. 21, 1989)). This declares that:

"[w]ith regard to the concept of discrimination (which is prohibited in Article 2 in respect of the rights guaranteed in the Covenant), the Committee noted that there was no definition of the term in the Covenant. However, drawing on the definitions included in other human rights treaties, the Committee considered that it should be understood to imply any distinction, exclusion, restriction or preference which is based on any ground such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status, and which has the purpose or effect of nullifying or impairing the recognition, enjoyment or exercise by all persons, on an equal footing, of all rights and freedoms."

Id.

¹⁹⁵ *Id.* at 42 (quoting U.N. Doc. CCPR/C/2/Rev. 1 (May 19, 1989)).

Even if the Committee on the Rights of the Child does interpret its powers to include authority to communicate its conclusions that at particular times and places violations of treaty obligations have occurred, the differences between "winning" and "losing" before the committee are blurred and far less dramatic than they are in the ordinary process of litigation. This is because the power to compel improvement by governments in their respect for human rights is generally by the process that has come to be known as "enforcement by shame," the power of national and international publicity to influence State Party behavior.

Thus it would, on the one hand, certainly be a powerful issue in any campaign to broaden a State Party's preventive health programs to claim publicly that the State Party is denying the human rights of newborn children and that the Committee on the Rights of the Child has demonstrably accepted the claim. It seems unlikely that a State Party would continue to fail to screen if the failure could be publicly and credibly proclaimed as a violation of international human rights law.

But even if that evaluation could not be added to the campaign for a medical screening program because the committee does not consider that the failure to establish the screening is a treaty violation, the campaign to secure it would not be fatally affected. A "no violation" conclusion of the committee does not mean that it supports a refusal to engage in the screening. In effect, an adverse evaluation by the committee on the violation issue only indicates that the matter of sickle cell screening is, in the circumstances, within the discretion of the State Party. Much of the "enforcement by shame" program that is afforded by the monitoring process of the Convention would remain, particularly the opportunities presented by that process to marshal public and professional opinion in favor of screening, and to press that opinion on the government.

VI. CONCLUSIONS

An internationally protected right to health for children has emerged in the new Convention on the Rights of the Child. It is the most elaborate and specific such guarantee to be found in international law. Nonetheless, its meaning, and whether it includes a right to the newborn medical screening that may be essential for the life and health of some children, cannot be ascertained from the text. The meaning of the right to health was not firmly established by the drafting process and cannot be developed without

some process of interpretation. The key issue is how and by whom that interpretation is to be made.

Those who see human rights law as providing only illusory protections commonly make the mistake of believing that governments are the sole interpreters of their obligations to respect human rights. It would be equally mistaken, however, to believe that the Committee on the Rights of the Child can, solely by reviewing reports submitted to it by States Parties, even if aided by expert advice, develop meanings of the right to health that can identify the particular health programs needed in a particular State Party at a particular time. Achieving this goal will require the initiative of organizations concerned with a children's right to health which advance and press claims for specific health programs. This initiative is an essential part of the legal process established by the Convention for defining and implementing its rights.

Law alone cannot significantly advance the health of children. But law—now international law—has a role to play in achieving that goal, especially if governments, private agencies, and other bodies such as UNICEF exploit the opportunities presented by the Convention.¹⁹⁶

¹⁹⁶ One of UNICEF's recent publications suggests a heightened awareness of the importance of international law to its mission. UNICEF, *STRATEGY FOR IMPROVED NUTRITION OF CHILDREN AND WOMEN IN DEVELOPING COUNTRIES* (1990). This publication begins with the statement that, "[f]reedom from hunger is a basic human right." *Id.* at 5. The Introduction that follows includes a full page documentation of the international instruments supporting the statement in the Summary, including quotations from relevant parts of Articles 6 and 24 of the Convention. *Id.* at 8. Nonetheless, the substance of this report is based on the assumption that there exists a national political will to commit resources to the problem. Its paragraph on advocacy includes no reference to using the Convention's mechanisms to obtain resources for better nutrition (*id.* at 32) and the discussion of UNICEF's collaboration with other agencies includes no mention of the opportunities assigned UNICEF in the work of the expert Committee on the Rights of the Child (*id.* at 33).