



March 24, 2009

Office of Public Health and Science  
U.S. Dept. of Health and Human Services  
Attention: Rescission Proposal Comments  
Hubert H. Humphrey Bldg.  
200 Independence Ave., SW  
Room 716G  
Washington, D.C. 20201

**Re: Proposed rescission of 45 C.F.R. Pt. 88 (“Ensuring that Dept. of HHS Funds Do Not Support Coercive or Discriminatory Policies or Practices in Violation of Federal Law”), 74 Fed. Reg. 10207-01 (Mar. 10, 2009).**

Dear Acting Secretary Johnson:

On behalf of the National Catholic Partnership on Disability<sup>1</sup> and the 14 million disabled Catholics it represents, I urge you not to rescind the “Health Care Provider Conscience Rule.” Rescission will expose providers to discrimination and coercion for attempting to protect disabled human life.

The history of people with disabilities and their treatment in the United States is one “that can only be called grotesque.”<sup>2</sup> For much of the last century, such people were banished from public life—hidden in back rooms,<sup>3</sup> excluded from common schools,<sup>4</sup> stored in institutions,<sup>5</sup> and often ‘neutered’ there “to prevent our being swamped with incompetence.”<sup>6</sup> Such mistreatment, an astute observer concluded, “in its virulence and

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<sup>1</sup> The National Catholic Partnership on Disability was established twenty-six years ago to implement the U.S. Catholic Bishops’ 1978 *Pastoral Statement on Persons with Disabilities*, available at [www.ncpd.org](http://www.ncpd.org).

<sup>2</sup> *City of Cleburne v. Cleburne Living Center*, 473 U.S. 432, 461 (1985) (Marshall, J., joined by Brennan & Blackmun, JJ., concurring in part & dissenting in part).

<sup>3</sup> For example, a Chicago ordinance once forbade those “diseased, maimed, mutilated, or in any way deformed so as to be an unsightly or disgusting object ... [from exposing themselves] to public view.” P. Longmore & E. Bouvia, “*Assisted Suicide and Social Prejudice*,” 3 *Issues in L. & Med.* 141, 144 n.18 (Fall, 1987) (quoting F. Bowe, *Handicapping America* 186 (1978)).

<sup>4</sup> See S. Rep. No. 168, 94th Cong., 1st Sess. 41 (1975) (estimating that over 1 million disabled children were then excluded from public schools).

<sup>5</sup> See *Wyatt v. Aderholt*, 503 F.2d 1305, 1313 (5th Cir. 1974) (quoting testimony of Dr. Gunnar Dybwad (“The situation which exists and obviously has existed in ... [the Alabama State School and Hospital for the Mentally Retarded] for a long time is one of storage, of persons. I am using that word because I would not use care, which involves- has a certain qualitative character, and I would not even use the word, ‘custodial,’ because custody, in my term, means safekeeping. ... [S]o I would say it is a storage problem at the moment.”)).

<sup>6</sup> *Buck v. Bell*, 274 U.S. 200, 207 (1927) (Holmes, J.) (Upholding constitutionality of compulsory sterilization of institutionalized retarded woman on grounds that “[t]hree generations of imbeciles are enough.”).

bigotry rivaled, and indeed paralleled, the worst excesses of Jim Crow.”<sup>7</sup> Once mainstreaming finally began, disabled people only found themselves “the poorest, least educated [and] largest minority in America [.]”<sup>8</sup>

The sad reality is that people with disabilities face even greater risks today. Present threats to life—abortion, euthanasia, and assisted suicide—are often aimed against disabling conditions. A fetal abnormality is routinely considered a death warrant, not a diagnosis.<sup>9</sup> Withholding food or treatment from certain disabled newborns has become an open secret.<sup>10</sup> Disabled adults are told that, by electing suicide with the caring help of others, they assert their autonomy by choosing to make themselves dead.<sup>11</sup>

Presently, pre-natal testing, such as amniocentesis, can detect about 70 different anomalous conditions.<sup>12</sup> Fetuses with Down syndrome, spina bifida, and anencephaly are virtually always aborted; those with less debilitating conditions, such as Turner and Klinefelter syndromes, are aborted more often than not.<sup>13</sup> Further, pre-implantation testing now permits the elimination of embryos immediately following a diagnosis of suspected genetic or chromosomal defects.<sup>14</sup> As detection improves and more anomalies are identified, abortions of disabled pre-natal life will increase. Rescinding Part 88 will undoubtedly compel many health care providers to choose between closing their doors, leaving their professions, losing their livelihoods or terminating these lives.

It is people of conscience—those doctors, nurses, and hospital administrators who refuse on moral and religious grounds to participate in such abortions—who take seriously the claim of American law that the presence of a disability does not lessen human worth.<sup>15</sup> As people with disabilities, we are indebted to their courage and stand with them to oppose rescinding regulations that will expose them to the violation of conscience. As people who value the sanctity of life because we have known its abuse, we can do nothing less.

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<sup>7</sup> *City of Cleburne*, 473 U.S. at 462 (Marshall, J., joined by Brennan & Blackmun, JJ., concurring in part & dissenting in part).

<sup>8</sup> S. Rep. No. 116, 101st Cong., 1st Sess. 9 (1989) (quoting statement of then Vice President George Bush).

<sup>9</sup> See Mansfield, et al., “Termination Rates After Prenatal Diagnosis of Down Syndrome, Spina Bifida, Anencephaly, and Turner and Klinefelter Syndromes: A Systematic Literature Review,” *Prenatal Diagn.*, 19: 808-812 (1999) (Down syndrome (95%), spina bifida (100%), anencephaly (100%), Turner syndrome (69%), Klinefelter syndrome (61%)).

<sup>10</sup> See S. Bondi, et al., “Neonatal Euthanasia?/In Reply,” 117 *Pediatrics* 983 (Mar. 1, 2006) (acknowledging that euthanizing neonates who suffer certain severe disabilities was “a practice that had been performed behind closed doors for many years.”).

<sup>11</sup> Cf. *Washington v. Glucksberg*, 521 U.S. 702, 731-732 (1997) (citations omitted) (“The Court of Appeals dismissed the State’s concern that disadvantaged persons might be pressured into physician-assisted suicide as ‘ludicrous on its face.’ ... We have recognized, however, the real risk of subtle coercion and undue influence in end-of-life situations. ... The State’s interest here goes beyond protecting the vulnerable from coercion; it extends to protecting disabled and terminally ill people from prejudice, negative and inaccurate stereotypes, and ‘societal indifference.’”).

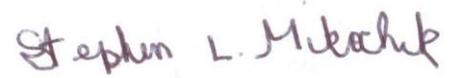
<sup>12</sup> See Baylor College of Medicine Medical Genetics Laboratories, “Abnormalities Detected V.5.0,” available at <http://www.bcm.edu/geneticlabs/cma/assets/abnormalities.pdf>.

<sup>13</sup> See *supra* note 9.

<sup>14</sup> See Sacred Congregation for the Doctrine of the Faith, Instruction “Dignitas Personae”: On Certain Bioethical Questions (June 20, 2008), available at [http://www.campchabad.com/roman\\_curia/congregations/cfaith/documents/rc\\_con\\_cfaith\\_doc\\_20081208\\_dignitas-personae\\_en.html](http://www.campchabad.com/roman_curia/congregations/cfaith/documents/rc_con_cfaith_doc_20081208_dignitas-personae_en.html).

<sup>15</sup> See, e.g., Americans with Disabilities Act, 42 U.S.C. § 12101 et seq.; Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794.

Respectfully submitted,



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