

THE NATIONAL CATHOLIC BIOETHICS CENTER

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November 13, 2023

U.S. Department of Health and Human Services Office for Civil Rights (OCR), Office of the Secretary, HHS Attention: HHS Grants Rulemaking (RIN–0945–AA15) Washington, DC 20201

Subj: Discrimination on the Basis of Disability in Health and Human Service Programs or Activities, 45 CFR 84, RIN 0945-AA15; Docket ID number HHS-OCR- 2023-19149.

Dear Sir or Madam:

The National Catholic Partnership on Disability (NCPD), the Catholic Medical Association (CMA), The National Catholic Bioethics Center (NCBC), and the National Association of Catholic Nurses, USA (NACN-USA) submit the following comments in support of, as well as concern pertaining to some provisions of the U.S. Department of Health and Human Services (HHS) proposed rule "Discrimination on the Basis of Disability in Health and Human Service Programs or Activities" (Proposal)

We wish to thank HHS for affirming the dignity of the human person, regardless of the presence of a disability, as demonstrated in the Proposal. The Proposal addresses the civil rights of individuals with disabilities under Section 504 of the *Rehabilitation Act* of 1973 (Section 504).² It would add new provisions that clarify existing requirements under Section 504 prohibiting recipients of financial assistance from the Department from discriminating based on disability in their programs and activities, including in health care, child welfare, and other human services. The Proposal includes new requirements prohibiting discrimination in the areas of medical treatment, child welfare services, reinterpreting the implementation of amendments to the *Rehabilitation Act*, the *Americans with Disabilities Act*⁴ of 2008, the *Affordable Care Act*,⁵ Executive Orders, as well as rulings of the U.S. Supreme Court and other court rulings. Specifically, the Proposal would amend its existing regulation implementing Section 504 for federally assisted programs and activities to address the obligations of recipients of Federal grants.

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¹ Federal Register, Thursday, September 14, 2023, Proposed Rules, 88 FR 63392-63512. https://www.federalregister.gov/documents/2023/09/14/2023-19149/discrimination-on-the-basis-of-disability-in-health-and-human-service-programs-or-activities.

² 28 CFR 35.104. - Section 504 of the *Rehabilitation Act* of 1973 (29 U.S.C.).

³ Americans with Disabilities Act of 1989, Public Law 336, U.S. Statutes at Large 104 (1990): 327-378.

⁴ 122 Stat. 3553 - ADA Amendments Act of 2008.

⁵ Public Law 111 - 148 - Patient Protection and Affordable Care Act (2010).

The National Catholic Partnership on Disability (NCPD) works with dioceses, parishes, ministers, and laity to promote the full and meaningful participation of persons with disabilities in the life of the Church. It promotes this ever-evolving mission to renovate and sustain ministry to-and-with all people with disabilities and their families through the following initiatives: leads and participates in trainings, workshops, and regional meetings; collaborates with the U.S. Conference of Catholic Bishops in revising guidelines, resources, and pastoral statements to foster these same ends; provides educational resources using a multitude of accessible media; participates in International Ecclesial Conferences; and advocates for policies that respect the full dignity and inclusion of all persons, especially those with varying abilities. The persons served directly or indirectly rely heavily on programs that would be impacted by this Proposal.

The National Catholic Bioethics Center (NCBC) is a faith-based organization engaged in bioethics publication, education and consultation to thousands of persons seeking its services. It has a membership of 1300 members, representing individuals, dioceses, parishes, health care corporations, educational institutions, among many others. Thus, the impact on membership far exceeds the official number of members. Through our consultation services increasingly we are made aware of challenges to religious freedom faced by individuals and institutions seeking to address the health and social services needs of the very populations served by HHS. These entities often rely on federal grants, partnering with the federal government to meet the needs of residents of the United States, and beyond.

The Catholic Medical Association (CMA) has over 2,400 physicians and allied health members nationwide. CMA members seek to uphold the principles of the Catholic faith in the science and practice of medicine—including the belief that every person's conscience and religious freedoms should be protected. The CMA's mission includes defending its members' right to follow their consciences and Catholic teaching within the physician-patient relationship, based on the patient's best interest. Members engage in this ministry of health within numerous secular as well as faith-based organizations sponsored by the Catholic Church, the largest provider of non-profit, non-governmental health care in the United States.⁶ There are numerous examples of Catholic sponsored ministries partnering with the federal government to meet critical health and social service needs, e.g., HHS awarding Catholic Charities of Trenton four million dollars to expand its Certified Community Behavioral Health Clinic, enhancing their efforts to treat addiction.⁷

The National Association of Catholic Nurses, USA (NACN-USA) is a non-profit organization of nurses from different backgrounds and specialties. NACN-USA shares the ministry of Catholic Nursing which advocates for human rights of vulnerable populations, and the rights of health care providers to protect those persons, as well as the rights of health care providers to have their own deeply held moral and religious beliefs protected. Through prayer, leadership, fellowship, education, and the formation of conscience, we strive to imitate Jesus Christ and His teachings. Our members endorse the dignity and sanctity of all human life from conception to natural death. We invoke the Holy Spirit and seek the protection of Our Lady of the Immaculate Conception.

The implications to the aforementioned organizations of some aspects of this Proposal, despite the positive aspects cited below, are very evident, especially considering the breadth of the definitions: "Program: (3)(i) An entire corporation, partnership, or other private organization, or an entire sole

⁶ Catholic Health Association of the USA, "Facts – Statistics: Catholic Health Care in the United States" (April 2023), Catholic Health Association of the USA. Retrieved from https://www.chausa.org/about/about/facts-statistics.

⁷ Federal Health Official: Community Collaboration Key in Cutting Overdose Deaths and Addiction, Catholic Charities, Diocese of Trenton (September 25, 2018). Retrieved from https://www.catholiccharitiestrenton.org/community-collaboration-key-cutting-overdose-deaths/.

proprietorship—(A) If assistance is extended to such corporation, partnership, private organization, or sole proprietorship as a whole; or (B) Which is principally engaged in the business of providing education, health care, housing, social services, or parks and recreation; or...." (§ 1630.2 Definitions). As the largest provider of non-governmental health, education, and social services in the United States, Catholic agencies have partnered with government in a positive way to meet the needs of the most vulnerable of our population. The proposed redefinition of disability that we address below will have tremendously negative consequences as we strive together to fulfill our mutual goals.

Positive Aspects:

We wish to express our support for the following provisions in the Proposal:

- Definitions and standards that defend the dignity of the human person, which remains intact despite the disabilities with which one may be born or acquire.
- The focus on protecting a person with disabilities' rights in four main specific areas:
 - Organ transplants Addressing concern that "people with disabilities who are otherwise qualified candidates for an organ transplant are excluded at many phases of the transplant process because of health care providers' inaccurate assumptions about quality of life, lifespan, and post-transplant compliance" (63397) However, we seek clarification concerning whether the rights of those with disabilities require a health care provider to engage in womb transplants, in violation of conscience or religious freedom?
 - Denial of life-sustaining care Addressing concerns that providers are deciding "that an
 intervention should not be provided if it 'fails to return or sustain an acceptable quality of life'
 for a patient in the judgment of the provider, even if the patient or their authorized
 representative would consider such an outcome acceptable;" and denials of care based on
 futility, e.g., "[S]ome sources have defined futility in terms of an inability to exit a hospital or
 institutional long-term care setting or a patient's reliance on others for activities of daily
 living." (63398; 63399)
 - Crisis standards of care (COVID-19) Existing standards are discriminatory, and the Proposal addresses this: "[M]any crisis standards of care protocols issued to prior to and during the COVID-19 public health emergency included categorical exclusions of people with disabilities from access to critical care despite their possessing the potential to benefit from treatment." (63400)
 - Participation in clinical research Should not be denied based on disability: "Recent research
 has documented that people with disabilities also face systematic and unnecessary exclusion
 from clinical research." (63401)
- Other significant applications of the rule against discrimination based on disability:
 - Denial of medical treatment It is illegal to deny or limit medical treatment "to a qualified individual with a disability when the denial is based on (i) bias or stereotypes about a patient's

⁸ U.S. Conference of Catholic Bishops, "Catholic Health Care, Social Services and Humanitarian Aid;" and "Education and workforce development" (ND). https://www.usccb.org/offices/public-affairs/catholic-health-care-social-services-and-humanitarian-aid.

disability; (ii) judgments that an individual will be a burden on others due to their disability, including, but not limited to, caregivers, family, or society; or (iii) a belief that the life of a person with a disability has a lesser value than that of a person without a disability, or that life with a disability is not worth living." A caregiver's decision must not be based on preconceived ideas about people with disabilities but by "consideration of effectiveness of the treatment or other legitimate reasons." (63403-04)

- Denial of Treatment for a Separate Symptom or Condition HHS intends to "address discriminatory conduct based on the belief that persons with disabilities are entitled to less bodily autonomy than persons without a disability—a belief that underpins the history of forced sterilization." Specifically, "a recipient may not deny or limit clinically appropriate treatment if it would be offered to a similarly situated person without under an underlying disability, including based on predictions about the long-term impact of the underlying disability of the individual's life expectancy." (63405-63406)
- Consent Section 504's prohibition on discrimination is not limited to situations in which providers are making decisions about medical treatments. It also includes "the provision of advice and the process of providing information to comply with informed-consent requirements established by state law and otherwise." "For example, a covered hospital may not repeatedly request that a patient with a disability (or the patient's legally authorized representative) consent to a do-not-resuscitate order, where it would not make such repeated requests of a similarly situated nondisabled patient." (63407-63408)
- Value assessment methods Must be assessed on a case-by-case basis: "Not all methods of value assessment or their uses are discriminatory. Many value assessment methods can play an important role in cost containment and quality improvement efforts. However... some value assessment frameworks... may discriminate on the basis of disability...." "Relying on a measure that discounts the value of extending the lives of people with disabilities... raises serious concerns in light of the consequences for access for individuals with disabilities." (63409-63410)

Concerns - "Gender Dysphoria:"

The Proposal relies on *Williams v. Kincaid*⁹ to state that "restrictions that prevent, limit, or interfere with otherwise qualified individuals' access to care due to their gender dysphoria, gender dysphoria diagnosis, or perception of gender dysphoria may violate section 504." 88 Fed. Reg. 63392, 63464. The Fourth Circuit, however, supported its argument by stating that the transgender plaintiff in *Williams* had a physical, rather than mental, disability through gender dysphoria because the plaintiff had to have hormone therapy as a treatment for the plaintiff's gender dysphoria. Moreover, the court cites to the fact that the plaintiff experienced "emotional, psychological, and physical distress" in declaring that such factors could lead to a reasonable inference of physical impairment.¹⁰

It appears that HHS is attempting to use Section 504 in these proposed regulations to create new nondiscrimination requirements for schools that receive federal financial assistance. This is especially problematic when one considers the Proposal's claim that gender dysphoria is considered a disability

⁹ Williams v. Kincaid, <u>45 F. 4th 759 (4th Cir. 2022)</u>, cert. denied <u>600 U.S. (U.S. June 30, 2023)</u> (No. 2-633).

¹⁰ *Id.*, at 770-771.

under Section 504: "Public schools that receive Federal financial assistance already must ensure they comply with obligations under other statutes such as the IDEA and Section 504 of the *Rehabilitation Act*. . . The proposed rule would add to and would not supplant the already robust framework for identifying children with disabilities and making materials accessible." (63440-41) However, *The Individuals with Disabilities Education Act* (IDEA) definition of "disability," is as follows:

(3) Child with a disability

(A) In general

The term "child with a disability" means a child—

- (i) with intellectual disabilities, hearing impairments (including deafness), speech or language impairments, visual impairments (including blindness), serious emotional disturbance (referred to in this chapter as "emotional disturbance"), orthopedic impairments, autism, traumatic brain injury, other health impairments, or specific learning disabilities; and
 - (ii) who, by reason thereof, needs special education and related services.

(B) Child aged 3 through 9

The term "child with a disability" for a child aged 3 through 9 (or any subset of that age range, including ages 3 through 5), may, at the discretion of the State and the local educational agency, include a child—

- (i) experiencing developmental delays, as defined by the State and as measured by appropriate diagnostic instruments and procedures, in 1 or more of the following areas: physical development; cognitive development; communication development; social or emotional development; or adaptive development; and
 - (ii) who, by reason thereof, needs special education and related services. 11

Thus, it is reasonable to infer that the meaning of "disability" under the *Americans with Disabilities Act* (ADA), Section 504 doesn't necessarily dictate what happens in the IDEA context. However, based on the Proposal one could obviously argue that gender dysphoria is an "emotional disturbance" existing "over a long period of time and to a marked degree" and thus a disability for purposes of the IDEA. ¹² Yet, the National Association of School Psychologists, the National Center for Lesbian Rights, the Human Rights Campaign, and the National Education Association have clearly held that identifying as LGBTQ is not a disability:

As defined by the Individuals with *Disabilities Education Act* (IDEA), a student with a disability is entitled to a Free Appropriate Public Education (FAPE) with an appropriately developed and implemented Individualized Education Program (IEP). The IEP must enable the student to make academic progress. While an LGBTQ student with a disability may face particular challenges and difficulties as a result of their sexual orientation, gender identity and/or gender expression, it is important to note that being LGBTQ is not a disability. While IEPs and 504 plans should not be used for LGBTQ students who have not been identified as having a disability, students may have health conditions (i.e., gender dysphoria, depression, anxiety)

¹¹ 22 U.S.C. § 1401(3).

¹² Individuals with Disabilities Education Act, Regulations: Statute/Regs Main » Regulations » Part B » Subpart A » Section 300.8 » c » 4.

related to their identity and/or orientation. In these cases, those conditions may warrant consideration as an educational disability or impairment.¹³

Thus, it is not the fact that a person identifying as LGBTQ has a disability pursuant to these statutes, but on a case-by-case basis a separate condition of an "emotional disturbance" involving dysphoria, depression, and anxiety may be the basis for the consideration of an educational disability under IDEA. Furthermore, the Proposal recognizes that Congress, in Section 512 of the *Americans with Disabilities Act* of 1990 (Pub. L. 101-336) (ADA) and the 1992 amendments to the *Rehabilitation Act* (Pub. L. 102-569) amended definitions in the federal *Rehabilitation Act* of 1973. In defining "disability" it excluded "transvestism, transsexualism, pedophilia, exhibitionism, voyeurism, gender identity disorders not resulting from physical impairments, or other sexual behavior disorders." Thus, Section 504 does not consider gender dysphoria a disability unless it is the result of a physical impairment, which is generally not the case. Despite this statutory exclusion, HHS claims that gender dysphoria is "not excluded from coverage under the ADA or section 504." This claim is based entirely on the Fourth Circuit's 2022 decision in *Williams v. Kinkaid*. However, as required by the ADA, there was no claim in the complaint identifying any part of Williams's body that is impaired or even allege any physical impairment. The ADA statute is clear, regardless of the interpretation of applicability of one specific case, which in so doing may be perceived as arbitrarily supportive of an HHS policy goal.

The proposed rule does not include language defining the phrase "solely by reason of disability." Such language constitutes critical regulatory criteria, and it is missing. For this, and the aforementioned reasons, the Proposal is creating confusion in terms of what obligations it creates for schools that receive federal assistance, and we seek clarification concerning these aforementioned contradictory implications:

- Does a school have an affirmative obligation to determine if students have disabilities?
- If so, what is a school's affirmative obligation to ask questions to find out whether its students have gender dysphoria?
- What does HHS claim a school must do to avoid discriminating against a student or athlete with gender dysphoria?
- What are the parameters to protecting free speech (forced speech, e.g., preferred pronouns)?

The Proposal also is creating confusion for the health care community. As noted above, the proposed rule claims that "gender dysphoria" would be a disability, but there is no language defining the phrase "solely by reason of disability." Adding to the confusion, the Proposal §84.4(a)(1) defines "disability" to include "a physical or mental impairment that substantially limits one or more of the major life activities of such individual." (63459) However, the administration's preferred interventions for this "disability" would render someone as having a disability under Section 504, e.g., the proposed rule states that the reproductive systems count as a "major life activity." Gender transition surgeries, puberty blockers and cross-sex hormones can permanently disable the reproductive system, creating "anatomical loss affecting one or more body systems," which by definition renders one as having a disability. (63459)

¹³ The National Association of School Psychologists, the National Center for Lesbian Rights, the Human Rights Campaign, and the National Education Association, *Advocating for LGBTQ Students with Disabilities: A Guide for Educators and Parents/Guardians on Supporting LGBTQ Students with an LEP or 504 Plan*, Human Rights Campaign Foundation (2020), p. 2. LGBTQ-Students-wDisabilities 111620 Final.pdf.

¹⁴ 29 U.S.C. 705(20)(F).

A number of questions are raised by the Proposal, not only for health care providers, as well as employers, but also those they serve:

- O What would this mean for transitioned people in general?
- What reasonable accommodations would be required for the employee who is transitioning or transitioned?
- What special rights or means of recourse would these disabling interventions raise for detransitioners?
- Would health care providers be forced by the government to violate conscience, requiring procedures considered to be mutilating to healthy anatomical functioning?
- Will the rights of those with disabilities require a health care provider to engage in womb transplants, in violation of conscience or religious freedom?

Similarly, social service agencies will be faced with the same aforementioned uncertainties, with added obligations to respect client rights, including privacy rights, and the need for a sense of security of all populations they serve. A number of these populations have vulnerabilities based on unrelated past traumas that must be respected. Furthermore, great sensitivities are needed in foster care and adoption policies, to assure the needs of the child are met, which must take precedence over those of those seeking to parent. Can an agency determine that a parent who has or is suffering with gender dysphoria or has transitioned may not be the best match for a child, with the child's own psychological needs, especially for a home with the presence of a father and a mother? What conscience and religious freedom policies of providers guaranteed by federal law, will be respected?

Concerns - Infants with Disabilities:

In 1984 HHS promulgated regulations ("Baby Doe" regulations) pursuant to an amendment to the *Child Abuse Prevention and Treatment Act* (CAPTA) of 1973. This was in response to reports that hospitals were denying infants with disabilities (such as Down syndrome) hydration and nutrition until death and refusing to address treatable conditions because of infants' disabilities. These regulations required federally funded health care providers to post a notice informing medical personnel about the civil rights of infants with disabilities, and required that state agencies take certain regulatory or enforcement steps ensuring that health care entities under their jurisdiction did not engage in discrimination against such infants. Hospitals sued these regulations, arguing that they should not be liable when parents had agreed with the decision to withhold life-saving treatment for their child. The U.S. Supreme Court ruled that the regulation was not authorized by Section 504. *Bowen v. American Hosp. Association*. The Court reasoned that the law only prevented discrimination against an "otherwise qualified" person with a disability; an infant with a disability cannot consent to treatment on his or her own behalf, and therefore is not "otherwise qualified" to receive life-saving treatment without parental consent. Based on this case law, HHS makes the following claims:

o HHS claims it is bound by *Bowen* and, by extension, cannot interpret Section 504 to protect the human dignity of infants with a disability whose parents do not want them kept alive. (63403)

¹⁵ 42 U.S.C. §§ 5102, 5103, 5103(b)(2), 5104.

¹⁶ 476 U.S. 610 (1986).

 HHS also claims that Section 504 does not apply to decisions to withhold treatment from infants with disabilities, in which the disabling condition is related to the condition to be treated. (63403)

Put together, HHS's position is that Section 504 only protects the human dignity of infants with a disability under the following conditions: (63403): the parents want their child to receive the treatment in question; and the treatment at issue is "for a separately diagnosable condition or symptom," not "for the underlying disability." To provide for treatment of a separate condition, but deny treatment for the underlying disability, represents discrimination against a child with a disability.

Clearly, this very conclusion is patently discriminatory against a child with a disability based on the presence of the disability, and should be removed as a condition for treatment. Clearly, a value judgment concerning the very dignity of the child, because of the disability, is being made. Prognostications often are wrong. A case in point is that of Baby Jane Doe, born with a meningomyelocele, hydrocephaly, microcephaly, and other anatomical anomalies. The parents refused surgical correction of the meningomyelocele but did provide conservative treatment. Months of litigation ensued and fortunately the meningomyelocele healed without surgery. However, the Court of Appeals concluded that the *Rehabilitation Act* did not give HHS any ability to interfere with the "treatment decisions involving defective newborn infants." Baby Jane Doe has intellectual and other disabilities, such as kidney damage and the need to use a wheelchair, but as of 2013, at the age of 30 years she could speak and lived in a group home, and celebrated her 30th birthday with her family. Such scenarios demonstrate the need for protections for persons with disabilities from what could be construed as passive euthanasia, as well as assisted suicide.

Physician Assisted Suicide; Active and Passive Euthanasia Concerns:

Persons with disabilities regardless of age or developmental stage, whom some of our signatories represent, have significant and reasonable concerns that proportionally beneficial treatment will be denied to them solely based on their disability. Case law is beginning to support such claims. A coalition of advocates for, and persons with disabilities have filed suit against the State of California: *United Spinal Association, et al., v. State of California, et al.*¹⁹ They seek to establish that California's assisted suicide law is a violation of the *Americans with Disabilities Act*, Section 504 of the *Rehabilitation Act*, and the equal protection and substantive due process clauses of the 14th Amendment of the U.S. Constitution. The plaintiffs are seeking healthcare equity – the basic care, long term services and supports, and durable medical equipment needed to live, which are compromised by California's so-called *End of Life Options Act* (EOLOA). They cite that under EOLOA, people with life-threatening disabilities and only people with life-threatening disabilities who say they want to die can get a state-facilitated death. Everyone else gets suicide prevention and the protections afforded by the law and professional standards. The plaintiffs have labeled this as discriminatory eugenics based on disability.

The ability to declare someone dead for organ donation who has a severe cognitive disability, without meeting the legal and professional "Total Brain Death" standard is in jeopardy, and of grave

¹⁷ Bowen v. American Hospital Assn., 476 U.S. 610 (1986), at 161.

¹⁸ Fuller, Nicole (13 October 2013). "Baby Jane Doe, center of debate in '80s, now 30." Newsday. Retrieved 2018-10-08.

¹⁹ United Spinal Association v. State of California, 2:23-cv-03107, (C.D. Cal.) Date Filed: April 25, 2023. Date of Last Known Filing: Oct. 27, 2023.

²⁰ California Health and Safety Code, Division 1, Part 1.85, Section 443-443.22. Amended 2021.

concern to persons with disabilities. This year the Uniform Law Commission has been considering a dangerous revision to the *Uniform Determination of Death Act*. ²¹ These are real threats to justice for communities we represent. The Proposal, unlike the Affordable Care Act²² is silent on prohibitions against Physician Assisted Suicide (PAS), and this needs to be remedied for PAS and for both active euthanasia and passive euthanasia (denial of proportionately beneficial treatment, e.g., infants with disabilities). Furthermore, we encourage HHS to incorporate into its proposal a 2021 HHS rule proposal—never finalized—that addressed the connection between the violation of disability rights and assisted suicide: Special Responsibilities of Medicare Hospitals in Emergency Cases and Discrimination on the Basis of Disability in Critical Health and Human Service Programs or Activities. 23 HHS developed this proposal so that there would be "greater clarity . . . under Section 504 regulations concerning discrimination regarding life-saving or life-sustaining services and life-ending items or services." "Consistent with Section 504's prohibition of discrimination on the basis of disability, the Department proposes to clarify that protections under Section 504 apply to discriminatory withdrawal or withholding of requested life-saving or life-sustaining care of individuals with disabilities for adults and infants alike, and to prohibit undue influence or steering of individuals toward the withdrawal of life-saving or life-sustaining care, or toward the provision of life-ending services, on the basis of disability." (p.14). We encourage HHS to incorporate into its proposal these provisions of the 2021 HHS proposed rule.

Conclusion:

Thank you for this opportunity to express our concerns, as well as our support for some of the provisions contained in the proposed rule, *Discrimination on the Basis of Disability in Health and Human Service Programs or Activities*. We wish to thank HHS for affirming the dignity of the human person, regardless of the presence of a disability, as demonstrated in the Proposal. We wish to express our support for the following provisions in the Proposal related to: denial of life-sustaining care, medical treatment, and treatment of symptoms and conditions; organ transplants; crisis standards of care; participation in clinical research, protection of informed consent. We agree there must be great caution in implementing Value-Assessment methods.

We have outlined in this letter our concerns as follows:

• It appears that HHS is attempting to use Section 504 in these proposed regulations to create new nondiscrimination requirements based on LGBTQ identity, for schools that receive federal financial assistance. This is especially problematic when one considers the Proposal's claim that gender dysphoria is considered a disability under Section 504. We have identified how there is not a legal basis for this claim. Section 504 does not consider gender dysphoria a disability unless it is the result of a physical impairment, which is generally not the case. Thus, it is not the fact that a person identifying as LGBTQ or with gender dysphoria has a disability pursuant to IDEA, the *Americans with Disabilities Act*, the *Rehabilitation Act* of 1973, and the 1992 amendments to the *Rehabilitation Act*.

²¹ Uniform Law Commission, "Determination of Death Act" (1980). https://www.uniformlaws.org/committees/community-home?communityKey=155faf5d-03c2-4027-99ba-ee4c99019d6c.

²² Amy Dockser Marcus, "Doctors and Lawyers Debate Meaning of Death as Families Challenge Practices Changing the determination of brain death potentially affects organ donation," *Wall Street Journal* (Dec. 11, 2022). https://www.wsj.com/articles/doctors-and-lawyers-debate-meaning-of-death-as-families-challenge-practices-11670761787?mod=Searchresults pos1&page=1.

²³ 42 CFR Parts 482 and 489 (2021). https://www.hhs.gov/sites/default/files/infants-nprm.pdf.

- The proposed rule does not include language defining the phrase "solely by reason of disability." Such language constitutes critical regulatory criteria, and it is missing. For this, and the aforementioned reasons, the Proposal is creating confusion in terms of what obligations it creates for schools that receive federal assistance; thus, we seek such clarification.
- The Proposal also is creating confusion for the health care community. As noted above, the proposed rule claims that "gender dysphoria" would be a disability, but there is no language defining the phrase "solely by reason of disability." Adding to the confusion, the Proposal §84.4(a)(1) defines "disability" to include "a physical or mental impairment that substantially limits one or more of the major life activities of such individual." (63459) However, the administration's preferred interventions for this "disability," by their very nature mutilate healthy functioning, thus rendering someone as having a disability under such a definition. What are the rights of those who wish to de-transition, and those who wish to assist them?
- A number of questions are raised by the Proposal, not only for health care providers, as well as
 employers, but also those they serve, concerning: reasonable accommodations; rights and recourse
 for both employee and employer; would health care providers be forced by the government to violate
 conscience, requiring procedures considered to be mutilating to healthy anatomical functioning?
- Similarly, social service agencies will be faced with the same aforementioned uncertainties, with added obligations to respect client rights, including privacy rights, and the need for a sense of security, of all populations they serve. Furthermore, great sensitivities are needed in foster care and adoption policies, to assure the needs of the child are met, which must take precedence over those of those seeking to parent. How are these concerns being addressed?
- HHS's position is that Section 504 only protects the human dignity of infants with a disability under
 the following conditions, regardless of whether the parents want their child to receive the treatment
 in question, if the treatment at issue is "for a separately diagnosable condition or symptom," but not
 if the treatment is "for the underlying disability." (63403) To provide for treatment of a separate
 condition, but deny treatment for the underlying disability, represents discrimination against a child
 with a disability. We urge rejection of this standard. Such standards demonstrate the need for
 protection for persons with disabilities from what could be construed as passive euthanasia, as well as
 assisted suicide.
- The Proposal, unlike the Affordable Care Act is silent on prohibitions against Physician Assisted Suicide (PAS), and this needs to be remedied for PAS and for both active euthanasia and passive euthanasia (denial of proportionately beneficial treatment, e.g., infants with disabilities). Furthermore, we encourage HHS to incorporate into its proposal a 2021 HHS rule proposal—never finalized—that addressed the connection between the violation of disability rights and assisted suicide: Special Responsibilities of Medicare Hospitals in Emergency Cases and Discrimination on the Basis of Disability in Critical Health and Human Service Programs or Activities. Furthermore, the ability to declare someone dead for organ donation who has a severe cognitive disability, without meeting the legal and professional "Total Brain Death" standard is in jeopardy, and of grave concern to persons with disabilities. This year the Uniform Law Commission has been considering a dangerous revision to the Uniform Determination of Death Act. These are real threats to justice for communities we represent.

Most notably the proposed regulations do not address the *First Amendment* or *Religious Freedom Restoration Act* protections usually afforded to religious individuals and institutions. This is especially concerning considering the ambiguity of the proposal's language: "No qualified individual with a disability shall, solely on the basis of disability, be excluded from participation in or be denied the benefits of the

programs or activities of a recipient, or be subjected to discrimination by any recipient." § 84.68 (a) Based on this language, many religious organizations will feel coercive pressure to abide by behavior contrary to their views on human sexuality and gender, creating a significant crisis of conscience. Moreover, as specifically applied to schools which receive federal funding, the proposed rule seems to force such schools to compromise their religious freedom to avoid being charged with "discrimination" based on gender dysphoria under the *Individuals with Disabilities Education Act* (IDEA).

Conscience protections for institutions that have a religious character would effectively be overturned by parts of these regulations. The Proposal, in addressing the term "disability," holds "that restrictions that prevent, limit, or interfere with otherwise qualified individuals' access to care due to their gender dysphoria diagnosis, or perception of gender dysphoria may violate Section 504 [of the *Rehabilitation Act* of 1973]." However, the very non-discriminatory provisions proposed have the grave potential of discriminating against grant recipients for their deeply held moral and religious beliefs protected by the U.S. Constitution's First Amendment, the *Religious Freedom Restoration Act* (RFRA), Title VII of the *Civil Rights Act* of 1964 (Title VII), Title IX of the *Education Amendments Act* of 1972, the Church Amendments, Section 245 of the *Public Health Service Act*, and the Weldon Amendment of the *Consolidated Appropriations Act*. This final Proposal, when finalized (Final Rule) must assure the religious and conscience protections guaranteed under these aforementioned laws and regulations.

Again, we thank you for the provisions that do protect the rights and dignity of persons with disabilities, and for providing us with the opportunity to identify those areas which would impede our ability to serve the millions of persons to whom we commit our services.

Sincerely yours,

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²⁴ Ibid., 63464.