

November 13, 2023

Via Federal eRulemaking Portal

Xavier Becerra
Secretary
U.S. Department of Health and Human Services
Office for Civil Rights
Attn: Disability NPRM, RIN 0945–AA15
Hubert H. Humphrey Building, Room 509F
200 Independence Avenue SW
Washington, DC 20201

Re: EPPC Scholar's Comment Regarding "Discrimination on the Basis of Disability in Health and Human Service Programs or Activities," RIN 0945-AA15

Dear Secretary Becerra:

I write in response to the Department of Health and Human Services' ("HHS") Proposed Rule, "Discrimination on the Basis of Disability in Health and Human Service Programs or Activities," RIN 0945-AA15 ("Proposed Rule"). I am a scholar at the Ethics and Public Policy Center (EPPC), where I serve as part of its HHS Accountability Project and a former attorney for the U.S. Department of Justice's Civil Rights Division. After leaving public service, I worked for the Becket Fund for Religious Liberty and in private practice, where I successfully defended the rights of religious employers and healthcare institutions from HHS's contraception mandate and transgender mandate.

My comments below also draw upon my vastly more important responsibilities as a father to a special needs child. Our son, Michael, was born with lissencephaly, a severe congenital neurological condition, and my wife and I worked hard to protect his health and his dignity until he passed away just short of his tenth birthday at the end of 2021. That experience gave my wife and me firsthand experience with many of the challenging situations the Proposed Rule seeks to address.

I support and am grateful for the Proposed Rule's efforts to add helpful clarity to Section 504's prohibition on discrimination on the basis of disability in the healthcare context. I encourage HHS to do more to apply the same conviction and clarity to two related scenarios: infants with disabilities and disabled persons considering assisted suicide.

Unfortunately, the same careful analysis and effort to provide clarity is lacking with regard to the Proposed Rule's claim that people with gender dysphoria qualify for protections under Section 504. This claim does not withstand scrutiny, HHS does not provide any indication that it has thought through this claim's implications, and says nothing about the enormous religious liberty problems such a claim would create. I urge HHS to drop this effort.

¹ 88 Fed. Reg. 63392 (Sept. 14, 2023).

I. The Proposed Rule offers helpful clarity to better protect the rights of people with disabilities in the healthcare context.

A substantial portion of the Proposed Rule is focused on "clarify[ing] the general prohibition on discrimination against qualified individuals with disabilities in the medical treatment context and elaborat[ing] on specific prohibitions in this context." This is an important and valuable service.

My institution, the Ethics and Public Policy Center, is dedicated to advancing a true and complete understanding of the human person. One of the many ways in which we do so is by defending the inherent dignity of the human person regardless of ability.

Though EPPC is not a Catholic institution, many of its scholars draw from the teachings of the Catholic Church, which has spoken powerfully to the dignity of the human person, including those with disabilities. Pope John Paul II articulated this tradition in an address he gave in 1984:

[T]o those suffering from disabilities and to those who offer them assistance. . . . I rejoice at the sensitivity being shown to our disabled and handicapped brothers and sisters . . . through worthy agencies, associations and institutions. . . . [T]he value and dignity of the human person does not arise from physical or mental qualities, from efficiency, productivity or speed in one's actions. It comes rather from the fundamental fact that each individual is created by God and redeemed by the blood of his Son Jesus Christ. God calls each of you by name. He wishes you to make your individual contribution to the world and to live life to the full in the service of others. God's fatherly care embraces the healthy and the sick, the disabled, the handicapped and the strong.³

Pope John Paul II also suffered with Parkinsons at the end of his life. He bore his disability with dignity and refused to retire from public life even as he declined. He did so that he might affirm—not only with his words but by his actions—that persons with disabilities have dignity and ought to have every opportunity to work and participate in public life. This powerful witness was noted at the time of JP II's death in 2005:

Theologians say the pope intended to use his suffering to give comfort to those similarly vulnerable or in pain. It was consistent with his defense of life in all stages, from the womb to old age.

"If the model of happiness in our culture is to be fit, trim, smiling and rising above the fray of anything that has to do with vulnerability or infirmity," said Peter Casarella, a theology professor at Catholic University, "then the pope is offering a very different version of human dignity: That which makes us most human is not the way we supersede life's troubles, but the way we deal with the challenges in life, including physical and spiritual suffering."...

"The pope lived openly with his disabilities, rejecting the notion that they needed to be hidden or feared, and in that way he did a service for people with disabilities worldwide, whether they're Catholic or otherwise," said Diane Coleman, who has spinal muscular

² *Id.* at 63395.

³ JP II, ¶ 4, *Apostolic Visit to Canada, Address of Pope John Paul II to Young, Elderly, and Handicapped People*, Vancouver Stadium, Tuesday, 18 Sept. 1984 (emphasis added), https://www.vatican.va/content/john-paul-ii/en/speeches/1984/september/documents/hf ip-ii spe 19840918 giovani-anziani.html.

atrophy and is president of Not Dead Yet, an organization that fights for the rights of the disabled and against assisted suicide and euthanasia. . . .

Lawrence Cunningham, a theology professor at the University of Notre Dame, said, "He had the idea that if I really believe in the gospel of life, then I've got to show that life is not all Botox and the hiding of disability, that one has to see through suffering to some kind of triumphant end. He had a very strong sense that if he preaches the gospel of life, then he has to live with whatever life deals him.

"I think that probably, in a certain sense, he was offering a critique of anyone who would make the argument that to become old or to become frail or to become infirm means automatically that you go off to the old nursing home."

By virtue of simply living his life, by not letting his Parkinson's stop him, John Paul showed that there is still a great deal of life to be lived for those with progressive or even terminal diseases, said Paul Longmore, director of the Institute for Disability Studies at San Francisco State University.

"We tend to assume that when you're sick or have a disability or are terminally ill that you're as good as dead and have nothing to offer and should abandon your work and the people around you," Longmore said. "He clearly did not do that."

As summarized below, the Proposed Rule affirms this same beautiful, ennobling vision of the human person. In its main provisions, the Rule asserts that it is wrong to discount the value of persons with disabilities and the lives they lead and it clarifies that covered entities face legal consequences if they fail to do so.

A. The Proposed Rule offers helpful clarity on what constitutes a discriminatory refusal to provide medical care.

The Proposed Rule identifies four specific areas in which persons with disabilities often face discrimination in the healthcare context. These areas are listed on page 63,396 of the Proposed Rule and each is described in more detail in the following pages:

- **Organ Transplants**: Addressing the concern "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."⁵
- **Denial of Life-Sustaining Care**: Addressing the concern 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." Recognizing the unjust and prejudicial reality that "some sources have defined futility in terms of an inability to exit a

⁴ Stephen Kiehl, *Public suffering offered comfort to the afflicted*, Baltimore Sun, April 4, 2005, https://www.baltimoresun.com/news/bs-xpm-2005-04-04-0504040107-story.html.

⁵ 88 Fed. Reg. at 63397.

⁶ *Id.* at 63399.

hospital or institutional long-term care setting or a patient's reliance on others for activities of daily living."⁷

- Crisis Standards of Care: Noting that "many 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."
- Participation in Clinical Research: Explaining that "[r]ecent research has documented that people with disabilities also face systematic and unnecessary exclusion from clinical research."

More broadly, the Proposed Rule offers concrete examples and makes clarifying statements about the sorts of actions that constitute illegal discrimination under Section 504 in the healthcare context. For example, the Proposed Rule clarifies what counts as discrimination on the basis of disability in the denial of medical treatment:

It is illegal to deny or limit treatment to a qualified individual with a disability when the denial is based on (i) bias or stereotypes about a patient's disability; (ii) judgments that an individual will be a burden on others due to his or her disability (including caregivers, family, or society at large); (iii) a belief that the life of a person with a disability has a lesser value, or even that life with a disability is not worth living.¹⁰

Denying, limiting, or withholding treatment [would be] discrimination on the basis of disability [if] the decision is driven by the recipient's perception of disability rather than by consideration of effectiveness of the treatment or other legitimate reasons.¹¹

The Proposed Rule also specifies that "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." HHS also seeks to "address discriminatory conduct based on the belief that persons with disabilities are entitled to less bodily autonomy than nondisabled persons—a belief that underpins the history of forced sterilization provided as 'medical treatment' for individuals with intellectual, mental health, and developmental disabilities." ¹³

B. The Proposed Rule affirms that healthcare providers can discriminate against the disabled in other ways as well.

The Proposed Rule stresses, however, that "Section 504's prohibition on discrimination is not limited to situations where 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)

⁸ *Id.* at 63400.

⁷ *Id*.

⁹ *Id.* at 63401.

¹⁰ *Id.* at 63403-04.

¹¹ *Id*.

¹² *Id.* at 63405.

¹³ *Id*.

¹⁴ *Id*. at 63407.

consent to a do-not-resuscitate order, where it would not make such repeated requests of a similarly situated nondisabled patient."¹⁵

The Proposed Rule notes the legitimate role that value assessment methods can play in making recommendations and other decisions about medical care. But it warns providers that they must take care to avoid implementing such models in a manner that discriminates against people with disabilities. "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. . . ."¹⁶ For example, "[r]elying 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."¹⁷

C. Suggestions to build on these principles.

The principles summarized above affirm the inherent dignity of every human life. I am grateful that HHS has taken this care to apply the broad prohibition against discrimination on the basis of disability in Section 504 and apply it to specific situations where disabled persons have faced discrimination. The Proposed Rule is all the more powerful because it provides compelling examples of instances where healthcare providers have or have not honored these principles, where they have succeeded or failed to properly value the lives of persons with disabilities.

As I mentioned in the introduction, my wife and I had the privilege of having a special needs son, Michael, who we cared for from his birth in July 2012, through his diagnosis with lissencephaly that fall, through a long series of family adventures and medical interventions, until he passed away at the end of 2021. We were blessed to have an excellent team of nurses, therapists, and doctors to help us care for Michael—throughout his life and in his last few days in the Pediatric Intensive Care Unit at Children's Hospital in Colorado Springs, Colorado. We could not have cared for him as we did without the help of people who shared our conviction that Michael's life had inherent value and that it was worth all of our efforts to give him the best quality of life we could. But I know that other families and individuals are not as fortunate. And for their sake I am grateful that HHS had developed this Proposed Rule.

I would ask that HHS consider whether there is anything more it can do, besides the notice described in proposed section 84.8, to make providers, beneficiaries, and other stakeholders aware of the rights of disabled persons as described in this Proposed Rule. I, for one, was not aware of any of these protections until I reviewed HHS's proposal. As I said, I am grateful that we never felt that any of our son's medical providers was discriminating against him or provided us with different options than they would another patient whose live they valued more. However, if I had been in such a situation, it would have been a great help to have known what my son's rights were and what steps I could take if I felt that those rights were being violated.

II. HHS should clarify that these general principles apply in full to infants with disabilities.

The Proposed Rule separately discusses how its proposed regulations under Section 504 apply to infants with disabilities. I was surprised and disappointed that these portions of the Proposed Rule did not seem to protect these disabled persons with the same zeal. It seems to me that this stems in part from what

¹⁵ *Id.* at 63408.

¹⁶ *Id.* at 63409.

¹⁷ *Id*.

¹⁸ See Kathryn Jean Lopez, Finding an intercessor in Michael Kniffin, Our Sunday Visitor, January 22, 2022, https://www.oursundayvisitor.com/finding-an-intercessor-in-michael-kniffin/.

I believe is an overly broad reading of the Supreme Court's 1986 decision in *Bowen v. American Hospital Association*, 476 U.S. 610 (1986), which I discuss below.

As the rule notes, HHS had decades ago promulgated regulations to clarify how Section 504 applied to situations where covered providers withhold medical care from infants with disabilities. ¹⁹ HHS developed these regulations in response to reports that hospitals were denying hydration and nutrition to infants with disabilities until the children died, as well as reports that hospitals were refusing to address disabled infants' treatable but fatal conditions. ²⁰

HHS describes how hospitals promptly brought suit against these regulations.²¹ A district court held the 1984 regulations invalid and enjoined their enforcement.²² The Supreme Court upheld the injunction in a plurality decision, but—as HHS notes—"of the seven justices who addressed the issue in *Bowen*, not one endorsed an injunction that would entirely bar the Secretary from regulating medical discrimination against disabled newborns."²³

Thus, since *Bowen*, one of the key questions in this area "is the extent to which the Department is able to issue regulations concerning newborn infants." ²⁴ In the Proposed Rule, HHS takes the position that the "*Bowen* injunction, as affirmed by the Supreme Court, [does not require HHS] to carve newborns out of this rule" altogether. ²⁵ HHS states that it is "follow[ing] the *Bowen* plurality in declining to require a recipient to provide medical treatment to an individual where the individual, or the person legally authorized to make medical decisions on behalf of that individual, does not consent to that treatment in situations where consent would typically be required regardless of whether the individual had a covered disability." ²⁶

I offer below comments as HHS finalizes regulations that apply Section 504 to disabled infants.

A. HHS properly notes that *Bowen* was a plurality decision.

First, HHS is correct to note that the Supreme Court did not issue a controlling decision in the *Bowen* case. In such cases, "when 'a fragmented Court decides a case and no single rationale explaining the result enjoys the assent of five Justices, the holding of the Court may be viewed as that position taken by those Members who concurred in the judgments on the narrowest grounds." I agree with HHS's assessment that the "narrowest grounds" among the concurring justices in *Bowen* limits the injunction "to cases in which the Department sought to require medical treatment despite a lack of parental consent." 28

B. HHS would not be bound by *Bowen* were it to develop a better factual record.

Second, HHS should not interpret *Bowen* as a hard ceiling on its ability to develop regulations protecting the rights of infants or other children with disabilities. As the Proposed Rrule notes, the plurality decision was based "on the particular facts of that case." The *Bowen* plurality itself also noted

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¹⁹ Id. at 63394 n.10.

²⁰ See 49 Fed. Reg. 1622 (Jan.12, 1984).

²¹ 88 Fed. Reg. at 63472 n.469 (citing *Bowen v. American Hospital Association*, 476 U.S. 610 (1986) (aff'g *Am. Hosp. Ass'n. v. Heckler*, 585 F. Supp. 541 (S.D.N.Y. 1984)).

²² *Id.* at 63472.

²³ *Id.* at 63408 and n.128.

²⁴ *Id.* at 63407.

²⁵ *Id.* at 63408.

²⁶ *Id*.

²⁷ Ramos v. Louisiana, 140 S. Ct. 1390, 1403 (2020) (quoting Marks v. United States, 430 U.S. 188, 193 (1977)).

²⁸ 88 Fed. Reg. at 63407.

²⁹ *Id.* at 63403.

on several occasions that its judgment that the regulations at issue were unlawful under the APA was predicated on its judgment that HHS had failed to develop the factual record:

In sum, there is nothing in the administrative record to justify the Secretary's belief that "discriminatory withholding of medical care" in violation of § 504 provides any support for federal regulation.³⁰

Although a hospital's selective refusal to report instances of medical neglect of handicapped infants might violate § 504, the Secretary has failed to point to any specific evidence that this has occurred. The 49 actual investigations summarized in the preamble do not reveal *any* case where a hospital either failed, or was accused of failing, to make an appropriate report to a state agency.³¹

[T]he Secretary's basis for federal intervention is perceived discrimination against handicapped infants in violation of § 504, and yet the Secretary has pointed to no evidence that such discrimination occurs.³²

The Proposed Rule does not appear to reflect the fact-bound nature of the Court's decision. HHS states that HHS is not retaining paragraphs (b)-(e) of § 84.55 "because they are subject to an injunction [in *Bowen*] declaring invalid and enjoying enforcement of those provisions." That is misleading. The *Bowen* plurality clearly left the door open for HHS to issue substantially similar regulations with the same aim—protecting the dignity and rights of children with disabilities—on a stronger factual record:

HHS has "substantial leeway to explore ways in which discrimination against the handicapped pos[es] particularly significant problems and to devise regulations to prohibit such discrimination."³⁴

I encourage HHS to seek comment from the public and to perform its own research to better understand the circumstances under which our healthcare system as a whole and healthcare providers—institutional and individually—discriminates against infants and other persons with disabilities. Based on such findings, HHS should continue to develop regulations to protect human dignity. It would be an error for HHS to conclude that *Bowen* precludes the Department from doing so.

C. Bowen does not prohibit HHS from investigating and developing regulations to protect infants with disabilities when parents do not consent to treatment.

Finally, HHS's Proposed Rule does not appear to recognize that the Department remains free to protect disabled children from discrimination even in situations where the child's parents refuse to give their consent. HHS states that it will "follow the *Bowen* plurality in declining to require a recipient to provide medical treatment to an individual where the individual, or the person legally authorized to make medical decision on behalf of that individual, does not consent to that treatment in situations where consent would typically be required regardless of whether the individual had a covered disability."³⁵ Exactly what HHS means by this statement is unclear.

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³⁰ Bowen, 476 U.S. at 636.

³¹ *Id.* at 637-38.

³² *Id.* at 643.

³³ 88 Fed. Reg. at 63472.

³⁴ Bowen at 643 (quoting Alexander v. Choate, 469 U.S. 287, 304 n.24 (1985)).

³⁵ 88 Fed. Reg. at 63408.

If HHS only means that it cannot and will not hold a covered provider liable under Section 504 *simply* for failing performing a medical procedure that a disabled child's parent did not consent to, then I agree. But if HHS interprets Bowen to hold that a covered provider cannot ever be liable under Section 504 for failing to treat a disabled child so long as the child's parent withholds consent, then I do not agree. The very next paragraph in the Proposed Rule shows this to be false.

As HHS explains, "Denial of treatment is not the only way a recipient can discriminate on the basis of disability in its covered programs or activities." "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." The Proposed Rule provides heartbreaking stories where doctors or hospitals have pressured the family members of disabled persons to forgo medical treatment that would extend their lives, even trying to convince the patient's loved ones that "live with the disability of quadriplegia was not worth living. This would be a violation of the proposed regulation under both 84.56(b)(1) and (c)(2)(ii)." 38

Covered provider discriminate in violation of Section 504 by pushing parents to consent to a donot-resuscitate order for a disabled child, where the same pressure would not be brought on parents of a non-disabled child. The flip-side is also true: covered providers discriminate in violation of Section 504 when they fail to seek parents' consent with the same zeal because the child in question has disabilities.

Finally, along the same lines, covered providers illegally discriminate against children with disabilities when they fail to report a child's parents to state authorities for failure to consent to a life-sustaining intervention if the provider would have made a report on behalf of a child that had no disabilities. The rules for when a provider must make such a report is a matter of state law. Nonetheless, a provider violates federal protections for disabled children when it carries out this reporting function in a discriminatory matter.

Nothing in the plurality's opinion in *Bowen* prohibits these applications of Section 504. In fact, many statements in the Justices' opinions support them. Furthermore, the general nondiscrimination principles summarized above compel them. I urge HHS to clarify in its final rule that all of the rights that persons with disabilities are entitled to under Section 504 apply with full force to persons in their earliest days after birth and that no Supreme Court decision says otherwise.

III. HHS should clarify that these general principles also apply to persons with disabilities in connection with assisted suicide.

Given the great care and sensitivity with which the Proposed Rule discusses how persons with disabilities face discrimination in the health care context, I was surprised that HHS did not discuss how disabled persons are discriminated against in the assisted suicide context.

Though proponents of assisted suicide promise that "strict procedures" will be put in place to ensure that assisted suicide would only be available to a very small population of people, there is much evidence that this is not what happens in practice. Last year in Canada the number of assisted deaths jumped more than thirty percent, accounting now for 4.1% of all deaths in Canada last year.³⁹

³⁷ *Id*.

News, Oct. 27, 2023, https://www.cbc.ca/news/politics/maid-canada-report-2022-1.7009704.

³⁶ *Id*.

^{3, 1}a.

³⁹ Benjamin Lopez Steven, *Number of assisted deaths jumped more than 30 per cent in 2022, report says*, CBC

The procedures appear to be particularly vulnerable when it comes to patients with disabilities. This concern is highlighted by a pending lawsuit in California, filed this past April. A lawsuit put together by people associated with the lawsuit states the following:

The lawsuit seeks 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. . . .

In [states that have legalized assisted suicide], there is a two-tiered system of law and medicine, where a medical professional would be subject to civil and professional liability if they did not provide non-disabled people or people with non-life-threatening disabilities suicide prevention, according to the standard of care, if those people expressed a desire to harm or kill themselves in a medical setting. If those same professionals actually helped the person kill themselves by providing the means, i.e., a prescription for a lethal dose of drugs, that medical professional would also be criminally liable under manslaughter statutes for helping another person die by suicide.

People with life-threatening disabilities, however, are not afforded the same criminal, civil, and professional liability protections as everyone else where assisted suicide is on the books. When they get suicide assistance on the basis of their disability, namely the condition that is given a 6-month or less prognosis, this is treating members of a protected class in a different way than everyone else, thereby violating the anti-discrimination law that protects the civil rights and inherent equal human dignity of people with disabilities.⁴⁰

Additionally, just this past May researchers published the largest study yet of how physician-assisted suicide is carried out in people with intellectual disabilities and/or autism spectrum disorders. The study of 39 Dutch case reports over a decade yielded the following chilling results:

Factors directly associated with intellectual disability and/or ASD were the sole cause of suffering described in 21% of cases and a major contributing factor in a further 42% of cases. Reasons for the EAS request included social isolation and loneliness (77%), lack of resilience or coping strategies (56%), lack of flexibility (rigid thinking or difficulty adapting to change) (44%) and oversensitivity to stimuli (26%). In one-third of cases, physicians noted there was 'no prospect of improvement' as ASD and intellectual disability are not treatable.⁴¹

As these sources show, individuals with disabilities are often pressured and coerced into preemptively ending their lives to avoid the alleged "burden" (financial or otherwise) they pose on their family or society. Additionally, insurance companies will have perverse financial incentives to push assisted suicide as a cheaper alternative to continuing to cover, sometimes expensive, medical care. When physicians are involved in assisting a person's suicide, they violate their oath to "do no harm" and corrupt the medical profession from being focused on healing to that of killing. The more individuals with disabilities are no longer part of society due to preemptive shortening of their lives, the less important folks will consider research and medical innovations to aid their quality of life.

⁴⁰ End Assisted Suicide, https://endassistedsuicide.org/ (emphasis added).

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⁴¹ Irene Tuffrey-Wijne, et al, *Euthanasia and physician-assisted suicide in people with intellectual disabilities and/or autism spectrum disorders: investigation of 39 Dutch case reports* (2012-2021). BJPsych Open. 2023 May 23;9(3):e87, doi: 10.1192/bjo.2023.69 (emphasis added).

I urge HHS to study this research and issue detailed findings and recommendations about how the protections under Section 504 apply in the assisted suicide context.

IV. HHS's claim that Section 504 prohibits discrimination on the basis of "gender dysphoria" is arbitrary and capricious and not supported by law.

The Proposed Rule takes a dramatic turn, however, when it departs from the main purpose of this rulemaking—to clarify the rights of disabled persons under Section 504—and claims that transgender persons diagnosed with "gender dysphoia" may now assert rights and bring claims under Section 504.

HHS acknowledges that proposed § 84.4(g) "is taken directly from the Rehabilitation Act, 29 U.S.C.705(20)(F), and is consistent with similar exclusions contained in the ADA" at 42 U.S.C. § 12211. 42 In the cited statutory provision, Congress explicitly excluded "transvestism, transsexualism, pedophilia, exhibitionism, voyeurism, gender identity disorders not resulting from physical impairments, or other sexual behavior disorders" from the definition of "disability" under the Rehabilitation Act.

Nonetheless, HHS asserts "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."43 This is an amazing claim—the sort of statement that gives lawyers and federal bureaucrats a bad name.

As HHS acknowledges, the American Psychiatric Association swapped out the term "gender identity disorder" for the new term "gender dysphoria" when it updated the DSM in 2013. According to The Advocate, "the world's leading source of LGBT news and information," the DSM "replace[d] the diagnostic term 'Gender Identity Disorder' with the term 'Gender Dysphoria." ⁴⁴ The reason this change was made was to remove the stigma that transgender persons face, not to designate a different condition.; "the new term implies a temporary mental state rather than an all-encompassing disorder, a change that helps remove the stigma transgender people face by being labeled 'disordered.'"45

HHS ignores this history. It cites only one authority in support of its claim that Congress' decision that Section 504 does not apply to "gender identity disorders not resulting from physical impairments" did not apply to people diagnosed with "gender dysphoria": Williams v. Kincaid, 45 F.4th 759 (4th Cir. 2022), cert. denied, 600 U.S. (U.S. June 30, 2023) (No. 22-633). But one circuit court case the law does not make. Importantly, the Supreme Court has never held that Section 504 covers gender dysphoria.

As my colleague Rachel Morrison has noted, the Proposed Rule is not the first time this administration has falsely claimed that gender dysphoria counts as a disability under Section 504; it was doing so even before the Fourth Circuit decided Kincaid. 46 In a March 31, 2022, letter to States Attorneys General, DOJ's Civil Rights Division stated:

⁴² 88 Fed. Reg. at 63464.

⁴⁴ Camille Beredjick, DSM-V To Rename Gender Identity Disorder 'Gender Dysphoria', The Advocate, July 12, 2012, https://www.advocate.com/politics/transgender/2012/07/23/dsm-replaces-gender-identity-disorder-genderdysphoria.

⁴⁵ *Id*.

⁴⁶ Rachel Morrison, Biden DOJ Letter Pushes Transgender Misinformation and Implies Gender Dysphoria Is a Disability, National Review, May 13, 2022, https://www.nationalreview.com/bench-memos/biden-doj-letter-pushestransgender-misinformation-and-implies-gender-dysphoria-is-a-disability/.

Section 504 of the Rehabilitation Act of 1973 protects people with disabilities, which can include individuals who experience gender dysphoria. 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 504.⁴⁷

As Rachel Morrison notes, this is a surprising position for the administration to take, given that "[t]he Left had long ago rejected the idea that homosexuality was in any way a disability, but simply a variant of normal. Is the Biden administration really conceding that gender dysphoria makes people so different that it counts as a disability? Or is it simply claiming disability nondiscrimination protections for those with gender dysphoria because it is politically expedient?"

Morrison's analysis notes that the letter from the Civil Rights Division failed to note that Congress specifically excluded "gender identity disorders not resulting from physical impairments, or other sexual behavior disorders" from the definition of disability under Section 504. Morrison concludes, "At best, the DOJ was sloppy with the letter's medical claims and legal analysis in the administration's rush to push gender ideology. At worst, the letter was a deliberate attempt to obfuscate the limits of gender medicine and the law in an attempt to 'encourage' state attorneys general to push the Biden administration's preferred policies over legal obligations."

The Proposed Rule at least recognizes this statutory exclusion, but HHS then states that it "agrees" with the Fourth Circuit's analysis in *Kincaid*. Unfortunately, however, HHS's analysis appears to be driven more by its ideological commitment to LBGTQI+ rights than its constitutional duties and its statutory obligations under the ADA and the Administrative Procedure Act.

My colleague Ed Whelan has written two separate posts dismantling the Fourth Circuit's opinion in *Kincaid*. Whelan first wrote in August 2022, after the Fourth Circuit issued its divided opinion.⁴⁸ He notes that the majority opinion claims that "gender dysphoria is categorically *not* a 'gender identity disorder' at all" because "when the ADA was enacted in 1990, the concept of 'gender identity disorders' did not include gender dysphoria."

By [Judge] Motz's illogic, the fact that the American Psychiatric Association removed "gender identity disorders" from its revised diagnostic manual in 2013 and substituted a narrower diagnosis of "gender dysphoria" somehow means that gender dysphoria is not a "gender identity disorder" under the ADA.

As Whelan shows, Judge Marvin Quattlebaum's dissent shows the illogic of the panel majority's analysis:

But as Judge Marvin Quattlebaum explains in dissent (slip op. at 38-47), the gender dysphoria that [plaintiff] Williams alleges—"discomfort or distress that is caused by a discrepancy between a person's gender identity and that person's sex assigned at birth (and the associated gender role and/or primary and secondary sex characteristics)"—"falls precisely under the [American Psychiatric Association's] description of, and diagnostic criteria for, gender identity disorders" in its diagnostic manual in effect in 1990. Indeed, Quattlebaum shows more broadly that "[f]rom 1990 to today, gender identity disorder has

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⁴⁷ DOJ, Civil Rights Division, Letter to State Attorneys General, March 31, 2022, https://www.justice.gov/opa/press-release/file/1489066/download.

⁴⁸ Ed Whelan, *Fourth Circuit's Transgender Dysphoria*, National Review, Aug. 17, 2022, https://www.nationalreview.com/bench-memos/fourth-circuits-transgender-dysphoria/.

been understood to include distress and discomfort from identifying as a gender different from the gender assigned at birth."

What's more, a gender identity disorder wouldn't even fall within the general definition of an ADA "disability" in the first place unless it resulted in an "impairment that substantially limits one or more major life activities of [an] individual." So it's precisely because the subcategory of gender dysphoria involves "clinically significant stress" that the exclusion comes into play.

Second, Motz maintains that even if gender dysphoria is a gender identity disorder under the ADA, Williams's complaint can plausibly be read to support the inference that his gender disorder "result[ed] from physical impairments." (Slip op. at 15-20.) But as Quattlebaum objects, the complaint does not identify any part of Williams's body that is impaired or even allege any physical impairment. (Slip op. at 50-53.)

Whelan wrote on the *Kincaid* decision again this summer after the Supreme Court declined the Fairfax County Sheriff's petition for certiorari. ⁴⁹ Whelan's post highlights portions of Justice Alito's dissent, which itself draws on Judge Marvin Quattlebaum's dissent.

Following my EPPC colleagues, I too find HHS's claim that "gender dysphoria" counts as a disability under Section 504 wholly unpersuasive. In addition to the powerful arguments my colleagues have already registered, I offer here a few additional comments and questions for HHS to consider that highlight the flaws in HHS's claim and the problem with its illegal effort to shoehorn transgender rights into Section 504.

A. Does HHS believe that Congress was aware of the term "gender dysphoria" when it adopted this exclusion in 1990?

The Proposed Rule credits the split panel's claim that it saw "no legitimate reason why Congress would intend to exclude from the ADA's protections transgender people who suffer from gender dysphoria." This argument presupposes that Congress might have considered this issue at all, which itself presupposes that the Congress that adopted this exclusion in 1990⁵¹ was at all aware of this term.

This seems extraordinarily unlikely. According to Congress.gov, the term "gender dysphoria" first appeared in the Congressional Record in 2008, nearly two decades after Congress adopted the definition at issue in *Kincaid*.⁵²

Before finalizing this Proposed Rule, I ask HHS to consider and answer the following questions:

• Does HHS believe that the members of Congress that voted to pass the ADA in 1990 were aware of the term "gender dysphoria" and had an opinion on how that term related to "gender identity disorders not resulting from physical impairments?"

⁴⁹ Ed Whelan, *Fourth Circuit's Transgender Dysphoria Evades Supreme Court Review*, National Review, July 3, 2023, https://www.nationalreview.com/bench-memos/fourth-circuits-transgender-dysphoria-evades-supreme-court-review/.

⁵⁰ 63464.

⁵¹ Pub.L. 101-336, Title V, § 512 (including the ADA statutory exclusion now found at 42 U.S.C.A. § 12211).

⁵² See Congress.gov, search term:

 $[\]underline{https://www.congress.gov/search?pageSort=dateOfIntroduction\%3Aasc\&q=\%7B\%22search\%22\%3A\%22\%5C\%22}\\gender+dysphoria\%5C\%22+\%22\%7D.$

- If not, does HHS claim that it has authority, consistent with the APA, to broaden the reach of a federal statute based on whether it sees "no legitimate reason why Congress would intend to exclude" from a statutory interpretation a novel term that there is no reason to believe Congress was aware of?
- If not, why does HHS believe that it may, consistent with its obligations under the APA, rely on the Fourth Circuit's decision in Kincaid?
- B. Can HHS rebut the charge that it either defers to or rejects caselaw not based on any reasoned basis but rather on whether the judicial decision aligns with its policy objectives?

As I and my colleagues in EPPC's HHS Accountability Project have noted on other occasions, HHS is consistently inconsistent in how it treats caselaw that bear on its policy preferences.

On the one hand, HHS considers itself free to disregard caselaw that interferes with its agenda. For example, in proposed rules issued February 2, 2023, HHS proposed to maintain a religious exemption to its "contraceptive services" mandate but eliminate the exemption for non-religious moral exemptions. 53 HHS acknowledges that a district court "reasoned that there was no rational basis" for "distinguishing between religious and moral exemptions."⁵⁴ But HHS summarily stated there that it "respectfully disagree[d]" with the court's decision. 55

Here, by contrast, HHS purports to expand Section 504 to count "gender dysphoria" as a disability—even though Congress excluded "gender identity disorders not resulting from physical impairments"—based on a single decision issued by a divided court. This fails to meet HHS's obligation to provide a "reasoned explanation" for its actions. 56

If HHS wishes to dispute this charge and defend its inconsistent treatment of caselaw, please answer the following questions:

- As a general matter, how does HHS decide whether to follow or to "respectfully disagree" with judicial decisions interpreting federal law or regulations?
- What criteria, besides HHS's policy preferences (and its realization that Congress does not share these policy preferences) informed HHS's decision to "respectfully disagree" with a federal court's determination that "there was no rational basis" for "distinguishing between religious and moral exemptions" from its contraception mandate but to "agree[]" with a federal court's judgment that it saw "no legitimate reason why Congress would intend to exclude from the ADA's protections transgender people who suffer from gender dysphoria"?
- Does HHS believe that its disparate treatment of caselaw meets its legal obligation to provide a "reasoned explanation" for its actions and avoid "arbitrary and capricious" determinations? If so, how?

⁵³ 88 Fed. Reg. 7236, 7249 (Feb. 2, 2023).

⁵⁴ *Id.* (citing *March for Life v. Burwell*, 128 F. Supp. 3d 116 (D.D.C. 2015)).

⁵⁶ F.C.C. v. Fox Television Stations, Inc., 556 U.S. 502, 516 (2009).

C. Are people who have received HHS's favored treatments for gender dysphoria thereby disabled under Section 504?

HHS asserts in the Proposed Rule that people with gender dysphoria may claim they are disabled under Section 504 and the ADA. HHS has elsewhere claimed that that it is "medically necessary" that people with gender dysphoria, including children, have access to "gender-affirming care," such as puberty blockers, cross-sex hormones, and so-called "gender-affirming surgery."⁵⁷

It is well established that what HHS calls "gender-affirming care" can have profound and permanent effects on the human body, which is one important reason why clinicians have increasingly been raising concerns over gender-transition interventions. ⁵⁸ Puberty blockers, originally praised as safe and fully reversible, are known to have negative effects on bone density, social and emotional maturation, and other aspects of neuro-development. ⁵⁹ This summer, the FDA issued a warning that puberty blockers can lead to vision loss. ⁶⁰ Puberty blockers generally fail to lessen the child's gender dysphoria, and deliver mixed results for mental health. ⁶¹ Long term effects remain unknown. ⁶²

In September, a FDA citizen petition was filed by "a coalition of physicians and organizations of parents, professionals in the healthcare field, individuals who have transitioned, and detransitioners dedicated to improving care for minors." The petition requested FDA "take urgent action concerning the off-label use of GnRH agonists, a class of drugs also known as puberty blockers," citing "the widespread—and rapidly growing—use of these drugs" by children to treat gender dysphoria and the "serious known and potential risks from these drugs," which have never been evaluated for safety and effectiveness for such use by the FDA. 64

Moreover, nearly all children who begin puberty blockers go on to receive cross-sex hormones, with life-altering consequences. ⁶⁵ Blocking a child's natural puberty prevents maturation of genitals and reproductive organs; subsequently introducing cross-sex hormones renders the child permanently sterile. ⁶⁶ Puberty suppression may also impair the child's later sexual functioning as an adult. ⁶⁷

Cross-sex hormones carry numerous health risks and cause significant irreversible changes in adolescents' bodies, including genital or vaginal atrophy, hair loss (or gain), voice changes, and impaired

⁵⁷ 87 Fed. Reg. 47824, 47834 (Aug. 4, 2022).

⁵⁸ William Malone, *Puberty Blockers for Gender Dysphoria: The Science is Far from Settled*, 5 Lancet Child & Adolescent Health 33 (2021), https://pubmed.ncbi.nlm.nih.gov/34418372/.

⁵⁹ NICE, Evidence Review: Gonadotrophin Releasing Hormone Analogues for Children and Adolescents with Gender Dysphoria (2021), https://cass.independent-review.uk/wp-content/uploads/2022/09/20220726_Evidence-review_GnRH-analogues_For-upload_Final.pdf.

⁶⁰ https://publications.aap.org/aapnews/news/20636/Risk-of-pseudotumor-cerebri-added-to-labeling-for

⁶¹ Polly Carmichael et al., *Short-Term Outcomes of Pubertal Suppression in a Selected Cohort of 12 to 15 Year Old Young People with Persistent Gender Dysphoria in the UK*, 16 PLoS ONE (2021), https://doi.org/10.1371/journal.pone.0243894.

⁶² Diane Chen et al., Consensus Parameter: Research Methodologies to Evaluate Neurodevelopmental Effects of Pubertal Suppression in Transgender Youth, 5 Transgender Health 246 (2020), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7759272/.

⁶³ Available at https://www.regulations.gov/document/FDA-2023-P-3767-0001.

⁶⁴ *Id*.

⁶⁵ *Id*.

⁶⁶ Stephen B. Levine, *Ethical Concerns About Emerging Treatment Paradigms for Gender Dysphoria*, 44 J. Sex & Marital Therapy 29 (2018), https://pubmed.ncbi.nlm.nih.gov/28332936/.

⁶⁷ Shrier, *supra* note Error! Bookmark not defined. Error! Bookmark not defined.

fertility. ⁶⁸ They increase cardiovascular risks and cause liver and metabolic changes. ⁶⁹ The flood of opposite sex hormones has variable emotional and psychological effects as well. Females taking testosterone experience an increase in gender dysphoria, particularly regarding their breasts, which heightens the likelihood they will undergo double mastectomies—as young as thirteen. ⁷⁰

Cross-sex hormones in turn increases the chances that an individual will proceed to surgery to have his or her primary and secondary sex organs amputated.

All of this is relevant here because the Proposed Rule defines disability to include a physical or mental impairment that substantially limits an individual's major life activities, including his or her reproductive system. The Proposed Rule also states that "anatomical loss affecting one or more body systems" also renders one disabled. 2

It thus seems that under HHS' interpretation of federal law, people with gender dysphoria are "disabled" under Section 504 and the ADA; and the "medically necessary" treatment for this "disability" also renders patients disabled under the Section 504 and the ADA.

In light of the following, please answer the following questions:

- Does HHS agree or disagree that people who receive what it calls "gender affirming care" are, depending on the procedure, either invariably or necessarily rendered "disabled" under the definitions proposed in this Proposed Rule?
- Are there any other disabilities HHS is aware of where HHS claims that that the "medically necessary" treatment for that disability renders the medical patient disabled in another way?
- Is it reasonable for a medical provider to refuse to render a patient disabled under Section 504 and the ADA if the medical provider believes there are other treatments available for the diagnosed condition that would not render the patient disabled?
- What, if any, additional informed consent protections are required before a medical provider can prescribe a pharmaceutical or perform a surgery that might or necessarily will render someone permanently disabled under Section 504?
- What impact, if any, do these observations and questions have on HHS's assertion that it is "discriminatory on its face" ⁷⁴ for a medical provider to categorically refuse to perform what HHS calls "gender affirming care," even when the medical provider in good faith believes

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⁶⁸ Levine et al., supra note Error! Bookmark not defined. Error! Bookmark not defined.

⁶⁹ *Gender-Affirming Hormone in Children and Adolescents*, BJM EBM Spotlight (Feb. 25, 2019), https://blogs.bmj.com/bmjebmspotlight/2019/02/25/gender-affirming-hormone-in-children-and-adolescents-evidence-review/.

⁷⁰ Johanna Olson-Kennedy et al., *Chest Reconstruction and Chest Dysphoria in Transmasculine Minors and Young Adults: Comparisons of Nonsurgical and Postsurgical Cohorts*, 172 JAMA Pediatrics 431 (2018), https://pubmed.ncbi.nlm.nih.gov/29507933/ (Figure: Age at Chest Surgery in the Post-surgical Cohort).

⁷¹ 88 Fed. Reg. at 63459 (describing Proposed §84.4(1)(1)); 63460 ("'Major life activities' includes . . . the operation of a major bodily function such as . . . reproductive systems").

⁷² *Id.* at 63459

⁷³ 87 Fed. Reg. 47871.

⁷⁴ *Id.* at 47872.

there are alternative treatments for someone with gender dysphoria that would not render the patient permanently disabled?

D. HHS must clarify and calculate costs of its proposed expansion of section 504 protections to gender dysphoria.

The Proposed Rule claims that gender dysphoria counts as a disability under Section 504 but fails to account for the massive impact and costs its proposal will have. Significantly, Section 504 and the ADA use identical language and are interpreted similarly. However, the ADA has a broader reach as it applies to employers. As such, it would seem that if HHS declares "gender dysphoria" to be a disability under Section 504 then the following would be considered discrimination based on gender dysphoria:

- So-called "misgendering" or not using a person's name, pronouns, titles, and honorifics that correspond to the person's gender identity;
- Not permitting a person to use bathrooms, locker rooms, showers, prison cells, and other sexspecific facilities that correspond to the person's gender identity;
- Having a sex-specific dress code and not permitting a person to dress consistent with their gender identity;
- Not providing so-called "gender affirming care" to a patient that suffers from gender dysphoria;
- Not providing insurance coverage for "gender affirming care";
- Not providing insurance coverage for other disabilities; and
- Offering counseling to encourage or help a person resolve their gender dysphoria by accepting and coming to peace with his or her biological sex;

To the extent that HHS's proposal applies to any of the above situations, I ask that HHS specify such application and reopen that proposal for public comment. As HHS states throughout the Proposed Rule, it has developed this proposal because it understands the need to create more "clarity" about what counts as discrimination under Section 504 and the ADA. As it stands, such unstated applications are not a logical outgrowth of the proposal, do not provide "clarity" about federal disability rights laws, and would be contrary to law. Additionally, to the extent that this proposal will impact interpretation of the ADA and the employment context, HHS should consult with Department of Labor and the EEOC. To fail to do so would be arbitrary and capricious.

Furthermore, to the extent that HHS believes that its proposal to extend Section 504 to gender dysphoria will result in any of the above applications, it must calculate the costs of such applications in its regulatory impact analysis. These calculations include, but are not limiting to:

- Increased insurance costs to cover what HHS considers "gender affirming care";
- Other costs associated with the accommodations HHS believes employers will have to offer in order to comply with its interpretation of Section 504; and
- Related training so that employers and employees are aware of these new legal obligations.

V. The Proposed Rule fails to account for its predictable impact on religious liberty.

HHS is well aware that its efforts to reinterpret federal law and create new legal rights for people that identify as transgender have a profound impact on this country's religious institutions. For example, its efforts to create a transgender services mandate under Section 1557 of the Affordable Care Act led to significant litigation across the country. In August 2022, the Fifth Circuit held that HHS's efforts to coerce religious healthcare providers into performing and insuring "gender affirming procedures" violated the Religious Freedom Restoration Act (RFRA) and affirmed the district court's issuance of a permanent injunction protecting the plaintiffs from HHS's illegal mandate. Last December, the Eighth Circuit issued a similar decision upholding a permanent injunction in favor of religious healthcare institutions, religious schools, and other religious employers. Last summer HHS decided to accept these decisions as final 177

In this Proposed Rule, HHS appears to be trying again to create a new transgender mandate through another means. Although most of the Proposed Rule discussed how Section 504 protects the rights of disabled persons in healthcare settings, HHS also discusses how Section 504 applies to schools that receive federal financial assistance and states that "this rule is intended to build on, but not to supplant those protections for students with disabilities." These new obligations would also presumably have to incorporate HHS's new claim that children with gender dysphoria are disabled under Section 504, and that covered schools therefore must update their Section 504 procedures "to identify children with disabilities."

Given that the stated purpose of this Proposed Rule is to "clarify existing requirements under section 504," it is unfortunate that HHS offers so little to help covered schools understand what exactly HHS's claim that gender dysphoria now counts as a disability under Section 504 means for them. It is even more troubling that HHS does not acknowledge that this new interpretation of Section 504 has important religious liberty implications and says nothing about how it will fulfill its obligation to recognize religious liberty rights under the Free Exercise Clause and the Religious Freedom Restoration Act.

In the final rule, HHS should clarify its position on what this new interpretation of Section 504 means for schools, including qualifying religious schools. HHS should likewise clarify how it will honor its obligations under the First Amendment and RFRA if it proceeds with its claim that gender dysphoria is now a disability under Section 504. It is irresponsible and unlawful for HHS to create new burdens on religious liberty without explaining how it will respect the rights of religious healthcare institutions, healthcare providers, medical professionals, schools, employers, employees, and other entities and individuals with sincere religious objections to complying with this mandate. HHS should specifically discuss how its provisions for religious liberty reflect the Fifth Circuit and Eighth Circuit precedents noted above. At a minimum, HHS's final rule should acknowledge the legal protections for religion identified by the Supreme Court in *Bostock*: the First Amendment ministerial exception, Title VII's religious organization exemption, and RFRA. ⁸⁰

Finally, it appears that the injunctions granted to plaintiffs in this Section 1557 litigation may also apply to these Proposed Rules under Section 504, given that Section 504 is one of the statutes that is

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⁷⁵ Franciscan All., Inc. v. Becerra, 47 F.4th 368, 380 (5th Cir. 2022).

⁷⁶ Religious Sisters of Mercy v. Becerra, 55 F.4th 583, 609 (8th Cir. 2022).

⁷⁷ Press Release: Federal Government Backs Down on Transgender Mandate, Becket (June 21, 2023), https://www.becketlaw.org/media/federal-government-backs-down-on-transgender-mandate/.

⁷⁸ 88 Fed. Reg. 63440-41.

⁷⁹ *Id.* at 63392.

⁸⁰ Bostock v. Clayton Cnty., Georgia, 140 S. Ct. 1731, 1754 (2020).

incorporated by reference into Section 1557. Does HHS believe that the injunctions in the Section 1557 litigation would apply equally to these regulations? If not, on what basis does HHS claim this new transgender mandate does not violate religious protection laws?

CONCLUSION

In finalizing this Proposed Rule, I urge the Department to keep the sections identified in Section I, which offer greater clarity as to the rights of persons with disabilities under Section 504. I urge HHS to clarify that these protections apply these protections with full force to infants with disabilities and to all persons with disabilities in the context of conversations and medical decisions related to so-called "assisted suicide."

I urge HHS to drop its unconvincing and unlawful attempt to claim that gender dysphoria counts as a disability under Section 504. HHS has not justified this interpretation of the law and has done almost nothing to explain what this new mandate would entail and anticipate what it would cost to implement. Dropping this aspect of the Proposed Rule would also solve the many religious liberty problems this aspect of the Proposed Rule would create. That, in turn, would save the federal government the millions of dollars in taxpayer money it would be compelled to spend defending this foolish mandate in court, and eventually paying religious organizations' attorneys fees after another predictable loss.

Sincerely,

Eric Kniffin, J.D.
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