November 13, 2023

U.S. Department of Health and Human Services
Office for Civil Rights
Hubert H. Humphrey Building, Room 509F
200 Independence Avenue SW
Washington, DC 20201
Submitted via regulations.gov

RE: Public Comment in Response to Discrimination on the Basis of Disability in Health and Human Service Programs or Activities [RIN 0945-AA15]

On behalf of the undersigned 27 organizations committed to researching and advancing the rights and well-being of lesbian, gay, bisexual, transgender, queer, intersex, and other sexual and gender minority (LGBTQI+) people in the United States, we write in response to the above-captioned notice of proposed rulemaking issued by the Department of Health and Human Services (the "Department") to amend its existing regulations implementing section 504 of the Rehabilitation Act of 1973 (Section 504) and provide clarity regarding its existing requirements (the "Proposed Rule").

We commend the Department for proposing to make its regulations on Section 504 more consistent with the approach taken by other agencies, including the Department of Justice (DOJ) and the Equal Employment Opportunity Commission (EEOC), in implementing statutory nondiscrimination protections for disabled people. The Proposed Rule is likewise consistent with other relevant statutes enforced by the Department like the Americans with Disabilities Act (ADA), as amended by the Americans with Disabilities Amendments Act of 2008, and Supreme Court and other significant court cases. We particularly commend the Department for its express inclusion of HIV within several key portions of the Proposed Rule, and for correctly recognizing in its preamble to the rule that statutory language excluding certain conditions from Section 504's protections does not include gender dysphoria. We hope that the Department will move to quickly finalize the Proposed Rule, and write to offer both our support for the rule and our recommendations for how its regulatory text could be further refined to fully encapsulate protections conferred by Section 504 that are of particular relevance to LGBTQI+ people.[1]

Research on LGBTQI+ People and Disabilities

Data from the Behavioral Risk Factor Surveillance System (BRFSS) indicate that LGBTQ+ adults, and transgender adults in particular, are significantly more likely than non-LGBTQ+

[1] "LGBTQI+" has become increasingly used by our organizations, the federal government, and other stakeholders to be expressly inclusive of intersex and other sexual and gender diverse people like asexual and pansexual populations. However, data limitations have often prevented intersex people, along with other LGBTQI+ subpopulations, from being consistently counted across various collections of data. We therefore will refer to "LGBTQI+" communities throughout the remainder of these comments, outside of where only particular subpopulations are being discussed by our referenced studies.

adults to self-report having at least one disability.[2] LGBTQI+ people are a growing population in the U.S., consisting of various subpopulations that reflect the breadth of diversity and lived experiences of the communities in which they live. Various research studies have found that younger people are more likely to identify as LGBTQ+.[3] According to data released by Gallup earlier this year, 7.2% of adults in the U.S. identify as LGBT.[4] LGBTQ+ people are a demographically diverse population, with the Williams Institute using Gallup Daily Tracking survey data from 2012–2017 to estimate that 12% of LGBT adults are Black, 1% identify as American Indian and Alaska Native, and 5% identify as more than one race.[5]

Intersex people—those with innate variations in their physical sex characteristics—are estimated to make up as much as 1.7% of the global population.[6] While intersex populations are distinct, they intersect considerably with other LGBTQI+ subpopulations; for example, intersex people as a group have distinct experiences from transgender and nonbinary populations, but overall are more likely to be transgender or nonbinary than non-intersex people. Intersex people and other sexual and gender minority populations share common challenges and experiences of social stigma, invisibility, and discrimination that are rooted in restrictive norms and stereotypes regarding gender and can in turn inform their experiences within medical settings. Data from a national survey of intersex adults, using measures borrowed from BRFSS, also found higher levels of self-reported disability than the general population.[7]

Research has long documented disabilities and persistent negative health outcomes—and therefore needs for ongoing medical care—among LGBTQ+ populations, including disparities in their physical and mental health when compared to their non-LGBTQ+ counterparts.[8] Available research on intersex people indicates that like LGBTQ+ communities more broadly, they face a

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[2] Human Rights Campaign Found., *Understanding Disability in the LGBTQ+ Community*, HUMAN RIGHTS CAMPAIGN (Aug. 12, 2022), https://www.hrc.org/resources/understanding-disabled-lgbtq-people.

[3] *See, e.g.*, SHOSHANA K. GOLDBERG ET AL., HUMAN RIGHTS CAMPAIGN & BOWLING GREEN STATE UNIV., EQUALITY ELECTORATE: THE PROJECTED GROWTH OF THE LGBTQ+ VOTING BLOC IN COMING YEARS (2022), https://hrc-prod-requests.s3-us-west-2.amazonaws.com/LGBTQ-VEP-Oct-2022.pdf. The Williams Institute has previously estimated that at least 2 million youth ages 13–17 identify as LGBT in the U.S., including approximately 300,000 youth who are transgender. JODY L. HERMAN ET AL., WILLIAMS INST., HOW MANY ADULTS AND YOUTH IDENTIFY AS TRANSGENDER IN THE UNITED STATES? (2022), https://williamsinstitute.law.ucla.edu/wp-content/uploads/Trans-Pop-Update-Jun-2022.pdf; KERITH J. CONRON, WILLIAMS INST., LGBT YOUTH POPULATION IN THE UNITED STATES (2020), https://williamsinstitute.law.ucla.edu/wp-content/uploads/LGBT-Youth-US-Pop-Sep-2020.pdf.

[4] Jeffrey M. Jones, *U.S. LGBT Identification Steady at 7.2%*, GALLUP (Feb. 22, 2023), https://news.gallup.com/poll/470708/lgbt-identification-steady.aspx.

[5] *LGBT Demographic Data Interactive*, WILLIAMS INST. (Jan. 2019), https://williamsinstitute.law.ucla.edu/visualization/lgbt-stats/?topic=LGBT#demographic.

[6] Melanie Blackless et al., *How Sexually Dimorphic Are We? Review And Synthesis*, 12 AM. J. HUMAN BIOLOGY 151 (2000), https://pubmed.ncbi.nlm.nih.gov/11534012.

[7] Amy Rosenwohl-Mack et al., *A National Study on the Physical and Mental Health of Intersex Adults in the U.S.*, 15 PLOS ONE e0240088 (2020), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7546494.

[8] *See, e.g.*, Kellan E. Baker, *Findings From the Behavioral Risk Factor Surveillance System on Health-Related Quality of Life Among US Transgender Adults, 2014-2017*, 179 JAMA INTERNAL MEDICINE 1141 (2019), https://jamanetwork.com/journals/jamainternalmedicine/fullarticle/2730765; Gilbert Gonzales & Carrie Henning-Smith, *Health Disparities by Sexual Orientation: Results and Implications from the Behavioral Risk Factor Surveillance System*, 42 J. COMMUNITY HEALTH 1163 (2017), https://pubmed.ncbi.nlm.nih.gov/28466199.

host of negative health outcomes often driven by inequality and social stigma.[9] An important example in this context is HIV, which affects Americans from all walks of life but disproportionately impacts members of the LGBTQ+ community, including "gay, bisexual, and other men who reported male-to-male sexual contact" and transgender women.[10]

According to the U.S. Centers for Disease Control and Prevention, there are over 1.2 million Americans currently living with HIV with approximately 30,000 people newly diagnosed every year.[11] In 2021, men reporting male-to-male sexual contact accounted for almost three-fourths (71%) of new diagnoses.[12] Researchers analyzing the results of the 2015 U.S. Transgender Survey found that transgender women are living with HIV at over eleven times the rate of the general population, with a staggering one in five Black transgender women living with HIV.[13] While advances in treatment have allowed people living with HIV to live long and productive lives, it remains a chronic condition requiring ongoing medical care. And unfortunately, people living with HIV have long reported experiencing discrimination in health care settings, including being outright denied access to care, because of their HIV status.[14]

Certain LGBTQI+ subpopulations also report distinct needs for health care that in turn can inherently leave them at a heightened risk of experiencing discrimination by medical providers. For example, chief among the drivers of health disparities observed between intersex and non-intersex people is the common practice of subjecting intersex people, often as infants, to nonconsensual, medically unnecessary surgeries intended to "normalize" their bodies.[15] The documented consequences of these nonconsensual operations, in addition to loss of potential fertility, include chronic pain, nerve damage, urinary incontinence, scarring, loss of future sexual function, PTSD, and an increased risk of suicide later in life.[16]

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[9] *See, e.g.*, Jane Ussher et al., *LGBTQI Cancer Patients' Quality of Life and Distress: A Comparison by Gender, Sexuality, Age, Cancer Type and Geographical Remoteness*, 12 FRONTIERS IN ONCOLOGY 873642 (2022), https://pubmed.ncbi.nlm.nih.gov/36203463; Henrik Falhammar, *Health Status in 1040 Adults with Disorders of Sex Development (DSD): A European Multicenter Study*, 7 ENDOCRINE CONNECTIONS 466 (2018), https://pubmed.ncbi.nlm.nih.gov/29490934.

[10] *HIV Diagnoses*, CDC.GOV (May 22, 2023), https://www.cdc.gov/hiv/statistics/overview/in-us/diagnoses.html; *see also* ILAN H. MEYER ET AL., WILLIAMS INST., LGBTQ PEOPLE IN THE US: SELECT FINDINGS FROM THE GENERATIONS AND TRANSPOP STUDIES 31 (2021), https://williamsinstitute.law.ucla.edu/wp-content/uploads/Generations-TransPop-Toplines-Jun-2021.pdf (noting that, in a nationally-representative sample of LGBTQ people, 3.6% of respondents indicated they were living with HIV).

[11] *HIV – Basic Statistics*, CDC.GOV (June 21, 2023), https://www.cdc.gov/hiv/basics/statistics.html.

[12] CDC.GOV, *supra* note 10.

[13] SANDY E. JAMES ET AL., NAT'L CTR. FOR TRANSGENDER EQUALITY, THE REPORT OF THE 2015 U.S. TRANSGENDER SURVEY 10 (2016), https://transequality.org/sites/default/files/docs/usts/USTS-Full-Report-Dec17.pdf.

[14] LAMBDA LEGAL, WHEN HEALTH CARE ISN'T CARING: LAMBDA LEGAL'S SURVEY OF DISCRIMINATION AGAINST LGBT PEOPLE AND PEOPLE WITH HIV (2010), https://legacy.lambdalegal.org/publications/when-health-care-isnt-caring.

[15] HUMAN RIGHTS WATCH, "I WANT TO BE LIKE NATURE MADE ME": MEDICALLY UNNECESSARY SURGERIES ON INTERSEX CHILDREN IN THE US (2017), https://www.hrw.org/sites/default/files/report_pdf/lgbtintersex0717_web_0.pdf.

[16] *Id.*

Likewise, gender dysphoria is a health condition that disproportionately affects transgender populations.[17] This condition can require ongoing care, increasing both the likelihood and impacts of encountering discrimination for many LGBTQI+ people already unfortunately likely to be subjected to such negative experiences throughout their lives. Research indicates that experiencing discrimination while in pursuit of health care is an acute fear for transgender people in particular: in a 2015 survey of more than 27,000 transgender adults, 33% of respondents who had seen a provider in the past year reported one or more negative experiences due to their transgender or gender non-conforming status.[18] In turn, 23% of respondents reported that they avoided seeking necessary health care when sick or injured in the past year because of fear of being mistreated as a transgender person.[19]

Experiencing discrimination and/or outright being denied access to medical care can have a direct impact on anyone's ability to respond to the health need they were seeking attention for, and for disabled LGBTQ+ people can easily cascade to further entrench negative health outcomes already prevalent among their communities. For example, while LGBTQ+ people have the same general risk factors as their non-LGBTQ+ counterparts with respect to suicide, research shows they report additional risk factors tied to experiences as LGBTQ+ people[20]—such as transgender people experiencing unique and additional distress when denied access to medically necessary gender-affirming care as part of their treatment for gender dysphoria.[21]

Support for the Proposed Rule

We strongly support the Department's Proposed Rule and urge that it be finalized as soon as possible. In particular, we applaud—and wish to emphasize the importance of—the Department's newly proposed regulatory provisions on discrimination in medical treatment[22] and value assessment methods,[23] as well as its proposed language that would prohibit disability-based discrimination in the informed consent process,[24] including through the provision of medical advice and the process for providing information on available treatment options.[25] Given our knowledge of pervasive discriminatory treatment decisions, denials of access to care, and decision-making criteria that devalue the lives of disabled people, these new provisions are essential protections against discrimination that has long impacted LGBTQI+ and non-LGBTQI+ people alike, and are consistent with both the purpose and case law of Section 504.

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[17] Kate Cooper et al., *The Phenomenology of Gender Dysphoria In Adults: A Systematic Review and Meta-Synthesis*, 80 CLINICAL PSYCHOLOGY REV. 101875 (2020), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7441311.

[18] JAMES ET AL., *supra* note 13, at 5.

[19] *Id.*

[20] *See, e.g.*, Amy E. Green et al., *Cumulative Minority Stress and Suicide Risk Among LGBTQ Youth*, 69 AM. J. COMMUNITY PSYCHOLOGY 157 (2021), https://onlinelibrary.wiley.com/doi/10.1002/ajcp.12553.

[21] JODY L. HERMAN & KATHRYN K. O'NEILL, WILLIAMS INST., SUICIDE RISK AND PREVENTION FOR TRANSGENDER PEOPLE: SUMMARY OF RESEARCH FINDINGS 2 (2021), https://williamsinstitute.law.ucla.edu/wp-content/uploads/Trans-Suicide-Summary-Sep-2021.pdf.

[22] Proposed § 84.56.

[23] Proposed § 84.57.

[24] Proposed § 84.56(c)(2)(ii).

[25] Proposed § 84.56(c)(2)(ii).

And in particular, we commend the Department for expressly including coverage against disability discrimination within the child welfare programs and activities it funds, and clarifying that this includes a prohibition on grantees taking action to deny parental, custody, or visitation rights, or the opportunity to participate in services and support programs—including family preservation and reunification services—for a qualified caregiver, foster parent, companion, or other prospective parent with a disability.[26] Research has long shown that LGBTQ+ youth are disproportionately represented in the child welfare system and often face discrimination and mistreatment in out-of-home care[27]—which can compound with discrimination they are likely to face[28] including for being disabled or cared for by someone who is disabled. Indeed, disabled people are often subjected to significant challenges when seeking to exercise their rights to be parents and caregivers, including by having their parental rights terminated based on their disability alone and without any evidence of abuse or neglect.[29]

Recommendations for Refining the Proposed Rule

While we are grateful for the Department's work in developing the Proposed Rule, we believe that its regulatory text requires further refinement to fully capture the protections provided under Section 504's broad scope. Below, we offer our recommendations for how the Department could improve this text within its anticipated Final Rule to reflect not only an accurate reading of the law, but also the lived experiences of disabled LGBTQI+ people.

Discrimination Against People Living with HIV

First, we note that we strongly support the Department's inclusion of HIV within the Proposed Rule's illustrative list of physical or mental impairments "that substantially limit[] one or more of the major life activities" of an individual claiming a disability for the purposes of Section 504,[30] as well as within its list of predictable assessments that *"*will, as a factual matter, virtually always be found to impose a substantial limitation on a major life activity" and therefore lead to

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[26] Proposed § 84.60. That being said, we recommend that the Department consider removing the qualifier "as determined by applicable State law" from its proposed definition of parents, see Proposed § 84.10, given other means of establishing legal parentage, such as through a marital presumption of parentage, which courts have long upheld even in the absence of express statutory language to that effect.

[27] *See* HUMAN RIGHTS CAMPAIGN FOUND., CARING FOR LGBTQ CHILDREN & YOUTH: A GUIDE FOR CHILD WELFARE PROVIDERS, https://assets2.hrc.org/files/assets/resources/HRC_Caring_For_LGBTQ_Children_Youth.pdf.

[28] We recommend the preamble to the Final Rule include discussion on how race and poverty intersect to impact the discussion of disability discrimination in this context, such as for indigenous and Black families for whom the rates of removal are disproportionately high. *See, e.g.*, *Gateway, Disproportionality Data*, U.S. DEP'T OF HEALTH & HUMAN SERVS., https://www.childwelfare.gov/topics/systemwide/cultural/disproportionality/data/ (last visited Nov. 6, 2023). Institutional placements have a disproportionate impact on Black and indigenous children and youth, who often stay in care longer, are segregated more from their non-disabled peers, and have poorer permanency outcomes than white children. *See* U.S. COMM'N ON CIVIL RIGHTS, THE MULTIETHNIC PLACEMENT ACT: MINORITIES IN FOSTER CARE AND ADOPTION (2010), https://www.usccr.gov/files/pubs/docs/MEPABriefingFinal_07-01-10.pdf.

[29] *See* NAT'L COUNCIL ON DISABILITY & CHRISTOPHER AND DANA REEVE FOUNDATION, PARENTING WITH A DISABILITY: KNOW YOUR RIGHTS TOOLKIT 5 (2016), https://www.ncd.gov/sites/default/files/Documents/Final%20508_Parenting%20Toolkit_Standard_0.pdf.

[30] Proposed § 84.4(b)(2).

a determination of coverage under Section 504.[31] **However, we recommend the Department amend its reference to HIV within the section on predictable assessments to be consistent with its reference to same within the list of physical or mental impairments, i.e., by stating that HIV is presumptively covered "(whether symptomatic or asymptomatic)".**

The language on HIV within the discussion on predictable assessments indicates that HIV was included because it "substantially limits immune function[.]"[32] However, we note that whether or not people living with HIV present with symptoms, HIV can damage their immune system, making it harder for their bodies to fight off infections and other diseases including heart disease, kidney disease, liver disease, and cancer.[33] Other agencies implementing protections similar to the Proposed Rule have previously received comments urging them to include the clarifying note that HIV is covered whether symptomatic or asymptomatic and we believe their approach in ultimately doing so is the correct one.[34] Such a change would reduce confusion among covered entities who might incorrectly believe that people living with HIV but without symptoms must be subjected to additional scrutiny in assessing whether their condition is an impairment that substantially limits a major life activity. The Department should ensure covered entities will be fully equipped to understand that "the necessary individualized assessment [for those seeking coverage under Section 504] should be particularly simple and straightforward"[35] for people living with HIV even in the absence of symptoms. Indeed, the determination of whether a person living with HIV has a disability should be presumptive and require no analysis at all. We ask the Department to clarify this point, consistent with the statutory language of the ADA, as amended, and its 2010 implementing regulations.

Discrimination Against People with Gender Dysphoria

Second, we recommend that the Department include language on Section 504's treatment of gender dysphoria as a qualifying disability within the Final Rule itself. We are in complete agreement with the Department that despite Section 504's language excluding "transvestism, transsexualism, pedophilia, exhibitionism, voyeurism, gender identity disorders not resulting from physical impairments, or other sexual behavior disorders" from the statute's definition of a qualifying disability,[36] gender dysphoria is not part of that exclusion. We are therefore grateful for the Department recognizing 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."[37]

As explained by the Fourth Circuit in *Williams v. Kincaid*, "a diagnosis of gender dysphoria, unlike that of 'gender identity disorder[],' concerns itself primarily with distress and other

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[31] Proposed § 84.4(d)(2)(iii)(J).

[32] *Id.*

[33] *HIV*, CDC.GOV (Oct. 19, 2022), https://wwwnc.cdc.gov/travel/diseases/hiv.

[34] 28 C.F.R. pt. 35 app. B (noting that "[t]he phrase 'symptomatic or asymptomatic' was inserted in [DOJ's] final rule after 'HIV disease' in response to commenters who suggested the clarification was necessary.").

[35] Proposed § 84.4(d)(2)(ii).

[36] 29 U.S.C. § 705(20)(F).

[37] 88 Fed. Reg. at 63464.

disabling symptoms, rather than simply being transgender."[38] We agree that gender dysphoria is a distinct condition from those named within the statutory exclusion, there is no legitimate reason why Congress would intend to exclude transgender people who suffer from gender dysphoria from the ADA and Section 504's protections, and the Proposed Rule's recognition of gender dysphoria as a qualifying disability reflects Congress's will that statutes like Section 504 and the ADA provide "maximum protection for those with disabilities[.]"[39] However, **we urge the Department to note its agreement with *Kincaid* within the text of the Final Rule itself to minimize the risk that covered entities that only see the statutory exclusion language in the regulatory text will incorrectly believe that the exclusion applies to gender dysphoria.**

The Department should provide a clarifying rule of construction within or after Proposed § 84.4(g) stating that:

> ***Rule of construction.*** **Gender dysphoria is not included in the scope of "gender identity disorders" or other conditions listed in paragraph (g)(1) of this section.**

Likewise, **we recommend that the preamble to the Final Rule include illustrative examples of the types of impermissible discrimination people with gender dysphoria might face, as the Proposed Rule's preamble currently includes none.** This should include examples of what discrimination can look like against someone who has both gender dysphoria and other disabilities, as additional challenges can present for people living at this intersection and especially when they are seeking access to gender-affirming care as treatment for their gender dysphoria. For example, some recent legislative and regulatory proposals have sought to enshrine barriers to gender-affirming care for disabled people—particularly those with intellectual, developmental, or mental health disabilities—based on the assumption that they are less capable of understanding or providing consent to this type of care.[40] We also understand some providers have imposed more stringent prerequisites on disabled people seeking gender-affirming care, or otherwise been reluctant to offer gender-affirming care to people with certain physical disabilities because of the need to provide them with disability-related accommodations.[41] We ask the Department to provide examples touching on these and other like scenarios[42] in its preamble to the Final Rule that are specific to gender dysphoria given the longstanding, erroneous belief held by some that this type of discrimination is not covered under Section 504.

Application of the Rule to Anti-Intersex Discrimination

Third, we recommend that the Department make clear that Section 504 prohibits discrimination against people with intersex variations. Under the Proposed Rule, all or nearly all individuals

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[38] Williams v. Kincaid, 45 F. 4th 759 (4th Cir. 2022), *cert. denied*, 600 U.S. ___ (2023).

[39] *Id.* at 769–70.

[40] *See, e.g.*, Orion Rummler & Sara Luterman, *Anti-Trans Laws Are Targeting Autistic Youth and Those With Mental Health Conditions*, THE 19TH (May 30, 2023), https://19thnews.org/2023/05/trans-laws-autistic-youth-mental-health.

[41] *See id.*

[42] *See, e.g.*, Abigail Mulcahy et al., *Gender Identity, Disability, and Unmet Healthcare Needs among Disabled People Living in the Community in the United States*, 19 INT'L J. OF ENVIRONMENTAL RESEARCH & PUBLIC HEALTH 2588 (2022), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8909748.

with intersex variations would qualify for protections through Section 504's "actual disability" prong, Section 504's "regarded as" prong, or both. **The Final Rule should make explicit reference to the applicability of protections for this population, and give examples illustrating how anti-intersex discrimination can arise under both prongs.**

Actual Disability

The ADA, as amended and incorporated into Section 504, defines "disability" broadly, and instructs that this definition "shall be construed in favor of broad coverage of individuals under this chapter, to the maximum extent permitted by the terms of [the statute]."[43] Likewise, Section 504's language broadly covers any physical condition that affects "the operation of a major bodily function," including "endocrine, and reproductive functions"[44] and was construed correctly by the Department to include the "genitourinary" system as well.[45]

We commend the Department for correctly construing the term "substantially limits" broadly as being "compared to most people in the general population," the assessment of which "usually will not require scientific, medical, or statistical evidence."[46] Section 504 is interpreted consistent with the ADA—and this definition is consistent with the statutory language, purpose, and intent of the ADA. Under these broad parameters, intersex variations will always or nearly always qualify by virtue of being physical conditions that affect how the endocrine, reproductive, and/or genitourinary systems are structured and function, which by definition is different than most of the population. While many intersex variations may cause only limited functional impairments, and may have little or no impact on daily life, these factors do not preclude them from qualifying as disabilities when they otherwise fall under Section 504's expansive definition.

To the extent that intersex individuals face discrimination specifically because of the results of past *medical interventions* related to their variation, this too is covered by Section 504. In accord with DOJ and EEOC regulations, the Department correctly construes Section 504 to prohibit discrimination because of an "*anatomical loss* affecting one or more body systems, such as . . . reproductive, . . . genitourinary, . . . and endocrine."[47] An anatomical loss of this type, which would presumably qualify as an actual impairment, can be caused by surgical procedures such as gonadectomies and genital-"normalizing" surgeries that are most commonly carried out in early childhood without proper informed consent.[48]

Regarded As

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[43] 42 U.S.C. § 12102(4)(A).

[44] *Id.* at § 12102(1)-(2).

[45] *See* Proposed § 84.4(b)(1)(i); 28 C.F.R. § 35.108(b)(1)(i) (DOJ); 29 C.F.R. § 1630.2(h)(1) (EEOC); *see also* Proposed § 84.4(b)-(c); 28 C.F.R. § 35.108(b)-(c) (DOJ); 29 C.F.R. § 1630.2(h)-(i) (EEOC).

[46] Proposed § 84.4(d); 28 C.F.R. § 35.108(d) (DOJ); 29 C.F.R. § 1630.2(j) (EEOC). As noted by the Department, this is not meant to be a demanding standard," or one under which a condition must "prevent, or significantly or severely restrict" a bodily function. *See* Proposed § 84.4(d).

[47] See Proposed § 84.4(b)(1)(i); 28 C.F.R. § 35.108(b)(1)(i) (DOJ); 29 C.F.R. § 1630.2(h)(1) (EEOC).

[48] The performance of such surgeries themselves may constitute disability discrimination prohibited by Section 504.

Additionally, the ADA, as amended and incorporated into Section 504, defines "disability" to include "being regarded as having" a disability.[49] Under this prong, it is unlawful to discriminate against a person "because of an actual or perceived physical or mental impairment," without regard to any actual or perceived "limitation."[50]

Due to widespread factual misunderstandings and persistent social stigmas, it is common for many people to assume that a person's intersex variation carries with it a type or degree of impairment that is either exaggerated or does not exist at all. For example, it is common both for laypersons and health care professionals to incorrectly assume that people with intersex variations are invariably and completely infertile. It is also common both for laypersons and health care professionals to assume that intersex variations will necessarily impair individuals' mental health, psychosocial functioning, ability to form and maintain romantic relationships, or sexual functioning. While factually dubious, such assumptions of serious mental, emotional, or sexual impairment have long been cited as justifications for early surgical and other medical interventions to alter or eliminate intersex traits. Individuals with intersex variations may also be assumed to have a certain type or extent of impairment based on an assumption about a co-occurring condition. Though these conditions may not always co-occur, both laypersons and health professionals may assume that an individual with a particular intersex variation also has certain impairments associated with an assumed co-occurring health condition.[51]

Recommended Language on Intersex People

The Department should provide, in the preamble to the Final Rule, one or more illustrative examples of discrimination against intersex people in health and human service programs. In the preamble to the Proposed Rule, the Department correctly recognizes that Section 504 applies with equal force to medical discrimination against patients of all ages, including newborns. We therefore recommend that the Department ensure these examples include discussion on discrimination against intersex infants and children in medical settings. Because of the frequency with which intersex children may be subjected to discriminatory medical treatment on the basis of stereotypes and misconceptions about their bodily variations, it would also be beneficial for the Department to **include a specific discussion of how the "regarded as" prong applies in these scenarios.** A relevant example to include in the preamble could describe a young child with the variation androgen insensitivity who is assigned female at birth and whose doctor performs a gonadectomy because he *regards* the child's internal testes as an impairment.

We strongly agree with the Department that involuntary sterilization, and any other involuntary, permanent, non-emergency medical interventions taken on a similar discriminatory basis, "is an important area in which to regulate in order to protect the rights of persons with disabilities."[52] **However, we are concerned that the Department's other statements regarding**

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[49] 42 U.S.C. § 12102(1)(C).

[50] *Id.* at § 12102(3)(A).

[51] There is evidence that some intersex variations have statistical correlations with other health conditions that are themselves associated with particular physical or mental impairments, such as Klinefelter's syndrome sometimes co-occurring with some type or extent of learning disability or developmental delay.

[52] 88 Fed. Reg. at 63406.

discriminatory sterilizations suggest unduly narrow protections for patients. To address these concerns, the Department should make clear that Section 504's application to discriminatory sterilizations applies to any procedures whose *expected and actual effect* is sterilization. Additionally, the Department should make clear that, regardless of the purpose *or* effect of a sterilizing procedure, the informed consent process for sterilizations is always subject to a Section 504 nondiscrimination analysis. The Department should make clear that this nondiscrimination analysis of medical informed consent processes must take account of any potential discrimination in compliance or noncompliance with otherwise-applicable patient protections (whether under federal, state, or local law, or private policy, contract, or established practice), including those that pertain to a particular medical context (including, but not limited to, a particular patient population, medical condition, or type of intervention, such as sterilizing procedures).

Application of the Rule to Other Department-Funded and Administered Health Programs

Finally, we recommend that the Department incorporate provisions into the Final Rule that explicitly recognize the "broader range of programs and activities by recipients of Federal financial assistance"[53] covered under Section 504 when compared to statutes like Section 1557 of the Affordable Care Act (Section 1557); specifically, its application to health insurers and other entities beyond traditional health service providers or those outside of traditional service delivery settings. As this proposal is intended to update and clarify the operation of Section 504 and the broad protections it establishes, **we strongly urge the Department to further parse out in the Final Rule how Section 504 and Section 1557 work together to protect disabled people from common discriminatory barriers that arise across the multiple types of health care entities that function within the complex American health care system.**

Health service providers have long been the focus of the Department's enforcement of both Section 504 and the ADA. Importantly however, the Department has recently noted its position that Section 1557 "applies only to health programs or activities[,]" while statutes like Section 504 "apply to all federally funded programs or activities[.]"[54] The wording of Section 1557 itself sweeps in "credits, subsidies, and contracts of insurance" as forms of federal financial assistance, with the Department's implementing regulations in turn seeking to ensure the right of disabled people to be free of discrimination in the programs or activities of entities that provide not only health-related services, but also health insurance and other health-related coverage.[55]

Despite this, **the Proposed Rule does not provide sufficient clarity as to how its provisions and Section 504 more broadly would apply to entities like health insurance providers. The preamble to the Proposed Rule even appears to state in error that provisions of the rule do not "relate to benefit design or other health insurance coverage issues."[56]** However,

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[53] *Id.* at 63483.

[54] Nondiscrimination in Health Programs and Activities, 87 Fed. Reg. 47824, 47844 (Aug. 04, 2022).

[55] *Id.* at 47842.

[56] 88 Fed. Reg. at 63483.

conceptually it can be difficult to distinguish where "benefit design" ends and where these myriad aspects of service delivery begin, and it is the purpose of Section 504 (in conjunction with statutes like Section 1557) to reach the many barriers for people with disabilities that can be embedded in these different facets of health care delivery.

Nor does the Proposed Rule address its application within carceral and other non-traditional settings where Department-funded programs and services are offered, and within which impacted individuals have reported significant rates of disabilities.[57] Notably, in states that expanded Medicaid, individuals transitioning into and out of incarceration recently became eligible for Medicaid coverage and could experience discrimination while seeking care within custodial and post-release settings that would implicate Section 504.[58]

Conclusion

We are grateful for this opportunity to provide comment on the Proposed Rule, and hope to see the Department issue a finalized regulation as soon as possible to ensure disabled LGBTQI+ and non-LGBTQI+ people alike will be able to access Section 504's important protections across the broad range of contexts covered by the statute where they are likely to encounter discrimination.

Thank you for your consideration of these recommendations. Please do not hesitate to contact Luis A. Vasquez, luis.vasquez@hrc.org, if you need any additional information.

Sincerely,

Human Rights Campaign
Bazelon Center for Mental Health Law
GLBTQ Legal Advocates & Defenders (GLAD)
National Center for Transgender Equality
Transgender Legal Defense & Education Fund
Silver State Equality-Nevada
Equality California
Los Angeles LGBT Center
National Action Network
CenterLink: The Community of LGBTQ Centers
Modern Military Association of America
The Leadership Conference on Civil and Human Rights
National Health Law Program
Community Catalyst
National Center for Parent Leadership, Advocacy, and Community Empowerment (National PLACE)

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[57] For example, nearly two in five (38%) state and federal prisoners reported having at least one disability in 2016. Laura M. Maruschak et al., *Disabilities Reported by Prisoners: Survey of Prison Inmates, 2016*, OJP.GOV (2021), https://bjs.ojp.gov/library/publications/disabilities-reported-prisoners-survey-prison-inmates-2016.

[58] EVELYNE P. BAUMRUCKER, CONG. RES. SERV., MEDICAID AND INCARCERATED INDIVIDUALS (2023), https://crsreports.congress.gov/product/pdf/IF/IF11830.

National Association of Social Workers
Campus Pride
Movement Advancement Project
National Women's Law Center
Disability Policy Consortium
SAGE (Advocacy and Services for LGBTQ+ Elders)
National Disability Rights Network (NDRN)
Japanese American Citizens League (JACL)
Mazzoni Center
Whitman-Walker Institute
Legal Action Center
Union for Reform Judaism