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DEPARTMENT OF HEALTH AND HUMAN SERVICES

[Docket No.: HHS-OCR-2021-0004]

RIN: 0945-AA15

45 CFR Part 84

Discrimination on the Basis of Disability in Critical Health and Human Service Programs or Activities

AGENCY: Office for Civil Rights (OCR), Office of the Secretary, HHS

ACTION: Request for Information.

SUMMARY:

Section 504 of the Rehabilitation Act of 1973, as amended, and its implementing regulation at 45 CFR Part 84 prohibit discrimination on the basis of disability in programs or activities that receive Federal financial assistance from the Department.

Specifically, Section 504 states:

No otherwise qualified individual with a disability in the United States, as defined in section 705(20) of this title, shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance or under any program or activity conducted by any Executive agency or by the United States Postal Service.

The Office for Civil Rights (“OCR”) is aware that significant discrimination on the basis of disability against persons with disabilities persists in the nation’s health care system and in its child welfare system. OCR has received reports of discriminatory

practices from researchers, advocates, organizations of persons with disabilities, and through its own work. The National Council on Disability (“NCD”), an independent Federal agency, has issued studies examining disability discrimination in health and human services and has recommended that OCR provide guidance, regulations, and increased enforcement with respect to multiple aspects of these issues as they relate to health and human services programs and activities funded by the Department.

As a result of this considerable input, and in light of OCR’s enforcement experience under Section 504, OCR has undertaken a review of its existing regulation and is considering revising it to address some of the most consequential and pressing disability discrimination issues that have been raised in health care and child welfare in recent years. To that end, OCR is soliciting feedback on such issues in these areas. Because of the extensive reach of the issues in these areas, it seems appropriate to solicit public comment on them.

OCR solicits public comment for the next 60 days on the issues that are identified below, and any additional issues that members of the public believe are important to addressing disability discrimination in the most important and pressing health care and child welfare contexts.

DATES: Submit comments on or before [INSERT DATE 60 DAYS AFTER DATE OF PUBLICATION IN THE *FEDERAL REGISTER*].

ADDRESSES: You may submit comments to this request for information, identified by RIN 0945-AA15, by any of the following methods:

- *Federal eRulemaking Portal*. You may submit electronic comments at <http://www.regulations.gov> by searching for the Docket ID number HHS-OCR-0004.

Follow the instructions at <http://www.regulations.gov> online for submitting comments through this method.

- *Regular, Express, or Overnight Mail:* You may mail comments to U.S.

Department of Health and Human Services, Office for Civil Rights, Attention: Disability RFI, RIN 0945-AA15, Hubert H. Humphrey Building, Room 509F, 200 Independence Avenue, SW, Washington, DC 20201.

- *Hand Delivery / Courier:* You may hand deliver comments to the U.S.

Department of Health and Human Services, Office for Civil Rights, Attention: Disability RFI, RIN 0945-AA15, Hubert H. Humphrey Building, Room 509F, 200 Independence Avenue, SW, Washington, DC 20201.

All comments sent by the methods and received or officially postmarked by the due date specified above will be posted without change to <http://www.regulations.gov>, including any personal information provided, and such posting may occur before or after the closing of the comment period.

We will consider all comments received or officially postmarked by the date and time specified in the “DATES” section above, but, because of the large number of public comments we normally receive on *Federal Register* documents, we are not able to provide individual acknowledgements of receipt.

Please allow sufficient time for mailed comments to be timely received in the event of delivery or security delays. Because access to the interior of the Hubert H. Humphrey Building is not readily available to persons without Federal government identification, commenters are encouraged to leave their comments in the mail drop slots located in the lobby of the building. Electronic comments with attachments should be in

Microsoft Word or Excel; however, we prefer Microsoft Word.

Please note that comments submitted by fax or email, and those submitted or postmarked after the comment period, will not be accepted.

Docket: For complete access to background documents or posted comments, go to <http://www.regulations.gov> and search for Docket ID number HHS-OCR-2021-0004.

FOR FURTHER INFORMATION CONTACT: Carla Carter at (800) 368–1019 or (800) 537–7697 (TDD).

DATE: January 15, 2021

Roger Severino,
Director,
Office for Civil Rights.

REQUEST FOR INFORMATION

SUMMARY OF ISSUES:

The issues with which OCR is soliciting comment on regarding disability discrimination include:

(1) discrimination on the basis of disability by covered health care entities in the provision of life-sustaining care, including in the context of organ transplantation, assisted suicide prevention services, health care value assessment methodologies, advanced care planning, Crisis Standards of Care, and other topics;

- (2) discrimination on the basis of disability by covered child welfare entities against children with disabilities, kinship caregivers, or prospective kinship caregivers with disabilities, parents with disabilities, or prospective adoptive, resource, and foster parents with disabilities, in the child welfare system; and
- (3) non-substantive, clarifying edits, including updating outdated terminology and references and eliminating unneeded references to the coverage of elementary and secondary education programs and activities in HHS’s Section 504 regulation.

SPECIFIC ISSUES AND QUESTIONS

ISSUE 1: Organ Transplantation

While the protections of the existing Section 504 regulation apply to health, welfare, and social service programs and activities associated with organ transplants that receive Federal financial assistance, mounting evidence suggests that individuals with disabilities are disproportionately denied access to life-saving organ transplants. On September 25, 2019, NCD submitted to the President its report, “Organ Transplants and Discrimination Against People with Disabilities.”¹ Among its key findings, NCD found the following:

- Disabilities unrelated to a person’s need for an organ transplant generally have little or no impact on the likelihood that the transplant will be successful.

¹ National Council on Disability, “Organ Transplant Discrimination Against People with Disabilities” *Bioethics and Disability Series* (Sep. 2019), https://ncd.gov/sites/default/files/NCD_Organ_Transplant_508.pdf.

- If such persons with disabilities receive adequate support, their disability should have very limited impact on their ability to adhere to a post-transplant care regimen.
- Doctors, clinicians and other medical experts who are a part of the process differ in perspectives with respect to whether people with disabilities should receive equal priority for organ transplants.
- There exists no uniform procedure in deciding eligibility for organ transplant.
- Disability-related policies vary greatly across the 252 organ transplant centers and are generally open to interpretation and potential insertion of disability biases.
- There is limited case law on the Americans with Disabilities Act and Section 504 in the organ transplant process. This is likely because organ transplantation is a time sensitive process and litigation can take years to resolve.
- Many organ transplant centers have policies that bar or caution against placing people with HIV, psychiatric disabilities, or intellectual and developmental disabilities (I/DD) on the waiting list to receive an organ transplant.
- Discrimination continues to occur in the nine states that have enacted laws explicitly prohibiting such discrimination.
- Existing organ procurement policies and practices do not adequately protect people with disabilities from being pressured to donate organs. For example, hospitalized people with disabilities facing possible withdrawal of life support are contacted, and even pressured, to donate their organs before a decision to withdraw life support has been made.
- Fair allocation of organs is a much-debated ethical issue – bringing to bear societal beliefs about the worth of a life of a person with a disability.²

Additionally, the report states that discrimination can and does occur throughout the organ transplant process. Generally, as set forth in the report, the four steps of the process are as follows: (1) the patient requests a referral from his or her physician to an

² *Id.* at 12-13.

organ transplant center (OTC); (2) the OTC conducts an evaluation to assess a patient's eligibility; (3) if (or when) the patient is determined to be eligible, the OTC places the patient on a national waiting list; and (4) if a match is found, the organ transplant occurs.³ In the report, NCD also points to a number of OTCs have written policies or practices that it believes clearly fail to follow Federal disability antidiscrimination law.⁴ OCR's investigative experience confirms that there are ongoing concerns about discrimination in organ transplantation. At various times over the past twenty years, OCR has received numerous complaints alleging discrimination on the basis of disability in organ transplantation.⁵ Most recently, OCR resolved a case alleging discrimination against an individual with autism whom the University of North Carolina Medical Center deemed ineligible to be on a heart transplant waiting list because of the individual's autism. OCR intervened in that case, and the medical facility agreed to change the individual's medical records, allowing the individual to be placed on the waiting list.⁶

On May 6, 2019, 17 major organizations that serve and advocate for individuals with disabilities sent a letter to OCR, with a copy to the Secretary of Health and Human Services, asking, among other things, that OCR issue a regulation and guidance that

³ *Id.* at 25.

⁴ *Id.* at 54.

⁵ *See, e.g., Bussoletti v. University of Pittsburgh Medical Center* (07-068765); *Walker v. University of California San Diego Medical Center* (08-80649); *Parsons v. County of Santa Clara, Santa Clara Valley Medical Center* (07-69439); *Paladino v. Union City Renal Center* (06-44878); *Beaton v. Sutter Memorial Hospital* (03-11505); *Eggemeyer v. Illinois Department of Human Services Randolph County Office* (03-004371); *HIV/AIDS Legal Services Alliance v. Health Plan P of California* (09-02-3296); *Lewis v. Willis Knighton Medical Center* (03-12129), on file with OCR. In at least one of the above complaints, OCR recommended that the covered entity evaluate its transplant listing policies after discovering that the covered entity's policy listed "severe mental retardation" as a contraindication for transplant.

⁶ *See* OCR "OCR Resolves Disability Complaint of Individual Who Was Denied the Opportunity for Heart Transplant List Placement," OCR Case No. 4-19-318735 (2019), <https://www.hhs.gov/about/news/2019/02/12/ocr-resolves-disability-complaint-individual-who-was-denied-opportunity-heart-transplant-list.html>.

addresses discriminatory practices in organ transplantation.⁷ The organizations cited several circumstances in which individuals with disabilities experienced discrimination in access to organ transplants.

On October 12, 2016, a bipartisan group of 30 members of Congress sent a letter to OCR, urging it to issue guidance on discrimination against individuals with disabilities, particularly individuals with developmental and intellectual disabilities, in organ transplantation. Their letter cited data documenting consideration of disability status in organ transplantation. For example, a 2008 survey of transplant centers found that 85% of pediatric transplant centers considered neurodevelopmental status as a factor in determinations of transplant eligibility at least some of the time and 71% of heart transplant programs always or usually considered neurodevelopmental status in determinations of eligibility.⁸

OCR has reviewed the body of research demonstrating the barriers that individuals with disabilities, particularly individuals with developmental and intellectual disabilities, face in seeking organ transplantation and finds it persuasive.⁹ In 2004, a survey by the National Work Group on Disability and Transplantation reported that only 52% of people with intellectual or developmental disabilities requesting referral to a specialist for evaluation of eligibility for an organ transplant receive such a referral, and 33% of these individuals who were given a referral were never evaluated for an organ

⁷ See Letter from Matt Valliere, Executive Director, Patients' Rights' Action Fund, and Diane Coleman, President and CEO, Not Dead Yet, on behalf of 17 organizations, to Roger Severino, Director, U.S. Dep't of Health and Human Servs., Office for Civil Rights (May 6, 2019). The letter is on file with OCR.

⁸ See Autistic Self Advocacy Network, *Organ Transplantation and People with I/DD: A Review of Research, Policy and Next Steps* (2013). https://autisticadvocacy.org/wp-content/uploads/2013/03/ASAN-Organ-Transplantation-Policy-Brief_3.18.13.pdf.

⁹ *Id.*

transplant.¹⁰ These barriers exist although many published cases show that individuals with intellectual disabilities that have received kidney transplants have successful outcomes and medical adherence rates comparable to those of the general population, and despite research findings that there is no ethical or medical reason for guidelines to consider developmental disability, in and of itself, a contraindication to heart transplantation.¹¹ A review of research literature that was published in *Pediatric Transplantation* indicated that scant scientific data would support the idea that intellectual or developmental disability would constitute a heightened risk of poorer outcomes in the aftermath of a transplantation procedure, provided that necessary supports in postoperative compliance protocols were provided.¹²

The Department is aware of media reports of various cases suggesting disability played a role in an organ transplantation controversy. For example, in 2012-13, the news widely covered the initial denial of a kidney transplant to a 3-year-old girl by Children's Hospital of Philadelphia because she had Wolf-Hirschhorn syndrome, which delays growth and developmental and intellectual abilities. After the family gathered over 50,000 signatures petitioning the hospital to allow the transplant, the child successfully received a kidney from her mother.¹³ In 2006, Oklahoma University Medical Center denied Misty Cargill a kidney transplant based on her mild intellectual disability.

¹⁰ The National Work Group on Disability and Transplantation, "Summary Report of Individual and Family Survey" (2004).

¹¹ E. Samuel-Jones, D.M. Mancini, and P.A. Shapiro, "Cardiac Transplantation in Adult Patients with Mental Retardation: Do Outcomes Support Consensus Guidelines," 53(2) *Psychomatics* 133-38 (2012).

¹² Marilee A. Martens, Linda Jones, and Steven Reiss, "Organ transplantation, Organ Donation, and Mental Retardation," 10.6 *Pediatric Transplantation* 658-64 (2006).

¹³ Kim Painter, "Disabled NJ Girl Thrives, Inspires After Transplant," *USA Today* (October 2013), <https://www.usatoday.com/story/news/nation/2013/10/05/disabled-transplant-amelia-rivera/2917989/>.

Although Misty was later put on a waiting list, she died before she could obtain a transplant.¹⁴

Discrimination has been driven by a variety of factors. Among these, OCR has observed that individuals with disabilities have been denied access to transplantation due to the views of physicians or organ transplant centers regarding their ability to manage the post-operative care needs associated with transplantation. The Department believes this is partly due to failures to consider how individuals with disabilities can manage their post-operative care needs with proper support. Under Federal disability nondiscrimination law, recipients must consider whether an individual would meet essential eligibility requirements with or without a reasonable modification of policies, practices, or procedures. In this context, assessors who consider only whether individuals can meet post-operative care requirements on their own are failing to comply with the law by failing to consider whether the individual can meet post-operative care with support or other resources. The ability to comply with post-operative care requirements without assistance is highly unlikely to ever be an essential eligibility requirement.

OCR, nevertheless, seeks more detailed information on how many patients are denied access to, or consideration for, the organ transplant list. We specifically seek comment from the public on any studies, surveys, or other information points that estimate the number or percentage of individuals denied placement on, or evaluation for, placement on the organ transplant list, especially for patients with underlying disabilities such as intellectual or developmental disabilities.

¹⁴ David Shapiro, “Disabled Woman Dies While Awaiting Second Chance at Transplant,” *NPR* (June 2012), <https://www.npr.org/sections/health-shots/2012/06/13/154914089/disabled-woman-dies-while-awaiting-second-chance-at-kidney-transplant>.

In addition, OCR is interested in any information as to the provision of reasonable modification in the organ transplant process. For example, whether and to what extent transplant programs receiving Federal financial assistance have deemed individuals with a disability unable to manage his or her post-transplant care needs because the individual is unable to do so independently, without the program having made reasonable modifications to their assessment process to account for the availability of formal or informal support systems that can assist individuals with maintaining compliance with the post-transplantation medical regimen, including support from family or friends, paid services, long-term services and supports, and other forms of assistance with respect to post-operative care. We request information on what different reasonable modifications would be appropriate in this context across the disability spectrum. We also seek information on appropriate reasonable modifications across a broad range of disability types. We are particularly interested in reasonable modifications for individuals with intellectual and developmental disabilities and individuals with a substance use disorder or a history of a substance use disorder. We also seek information on the frequency of denials of transplantation across disability types, including intellectual and developmental disability and substance use disorder, as well as the frequency of denials for potentially discriminatory reasons. We also request information as to whether there are other instances of potential discrimination in the organ transplantation context that OCR should seek to specifically address in the future.

**ISSUE 2: Life-Saving or Life-Sustaining Care: Medical Futility and Quality of Life
Judgments**

Issues involving life-saving or life-sustaining care—in particular decisions on medical futility for individuals with disabilities and withdrawal of medical care against the wishes of a patient or his or her legal representatives—implicate important civil rights and must be approached with close attention to the nondiscrimination requirements of Federal disability rights law. A significant body of evidence from stakeholders, researchers, and advocates shows that individuals with disabilities face discrimination of various kinds in the provision of life-saving or life-sustaining care, and that there is often confusion on the part of providers about their obligations under Section 504. In addition, the report of the National Council on Disability, “Medical Futility and Disability Bias,” which is part of NCD’s Bioethics and Disability Series, concluded that decisions by healthcare providers to withhold or withdraw life-saving or life-sustaining care for individuals with disabilities are often driven by subjective quality-of-life judgments that are impermissible under Federal disability rights law. As detailed in its recently issued Notice of Proposed Rulemaking on Special Responsibilities of Medicare Hospitals in Emergency Cases and Discrimination on the Basis of Disability in Critical Health and Human Service Programs or Activities, the Department recognizes a long and persistent history of discrimination among people with disabilities in situations regarding the provision or withdrawal of life-saving or life-sustaining care and related pressure from providers covered by Section 504 and recognizes that greater clarity is needed under Section 504 regulations concerning discrimination regarding life-saving or life-sustaining services and life-ending items or services.

Within the recently issued NPRM, the Department proposed to clarify that protections under Section 504 apply to discriminatory withdrawal or withholding of requested life-saving or life-sustaining care of individuals with disabilities, and to prohibit undue influence or steering of individuals toward the withdrawal of life-saving or life-sustaining care, or toward the provision of life-ending services, on the basis of disability. The rule would also clarify that the protections against discrimination for individuals with disabilities apply to decisions to withdraw life-saving or life-sustaining care on the basis of evaluations of the relative worth of life based on disability, or a contention or assessment that an individual does or would impose a burden on caregivers or society based on disability, or on illegal stereotypes or bias based on disability, whether assessed based on the individual's status prior to receiving life-saving or life-sustaining care or anticipated status after receiving life-saving or life-sustaining care.

The rule would clarify that conditions or symptoms constituting or regarded as disabilities may only be considered as factors in deeming that a life-saving or life-sustaining treatment or service is futile, unnecessary, or inappropriate for an individual if the provider makes an individualized assessment of the relevance of such conditions or symptoms to the individual's short-term survivability and considers available auxiliary aids and services and reasonable modifications for alleviating or mitigating such conditions or symptoms. Likewise, the rule would specify criteria that hospitals shall not use as a basis for determining a treatment or service unnecessary or inappropriate.

Further, the rule would assert in Section 504 and the CMS Facility Regulations that these protections include a prohibition on covered entities' steering, encouraging, pressuring, or unduly influencing an individual, or his or her legal representative,

including a parent or guardian of an individual with a disability, on the basis of discriminatory factors specified in the regulation, to decline or withhold consent for the provision of life-saving or life-sustaining care; to consent to the withdrawal of life-saving or life-sustaining care; or to consent to the provision or receipt of any life-ending item or service (*i.e.*, assisted suicide, euthanasia, or mercy killing). The Department strongly believes that patients and their legal representatives must receive the complete information necessary to make informed decisions about their care, and seeks information about how covered entities can provide complete information without steering patients in a discriminatory manner described in the rule.

While the Department encourages comment on these issues within the NPRM, it also seeks comment under this Request for Information, recognizing that they may reach different audiences and that there may be a broader scope of topics relevant to life-saving or life-sustaining care, medical futility and quality of life judgments than those articulated within the proposed rule. Where relevant, we encourage comment under both the NPRM and this request for information.

Disability rights and civil liberties organizations have expressed serious concern regarding disability discrimination in medical futility decisions. A July 10, 2018 letter from 22 disability organizations to OCR Director Roger Severino and to Lance Robertson, Administrator of HHS's Administration for Community Living and Assistant Secretary for Aging, noted that sometimes, medical determinations of futility are motivated by inappropriate consideration of cost or value judgments regarding the quality of life of individuals with disabilities seeking life-saving or life-sustaining medical treatment rather than an objective assessment of the individual's ability to benefit from

treatment.¹⁵ While cost may be a factor for decision-making under Section 504, it should not justify a determination of futility, which should be determined solely based on clinical factors. As reflected within the recently issued NPRM, the Department believes that evaluations of the relative worth of the life of an individual with a disability or disabilities compared to a person without the disability or disabilities are an impermissible reason to deny care or withdraw life-saving or life-sustaining care sought by an individual or their legal representative.

On May 6, 2019, a coalition of 17 leading organizations that advocate for or serve individuals with disabilities wrote to OCR, raising certain disability discrimination issues.¹⁶ They pointed to “so-called ‘futile care’ laws and policies, which allow doctors to deny life-sustaining treatment to individuals with disabilities who want and need it.” On September 3, 2019, the American Civil Liberties Union wrote a letter to OCR, highlighting that medical futility determinations are an area of concern for discrimination against individuals with disabilities.¹⁷

Medical futility determinations allow physicians and hospitals to discontinue – or not provide in the first place – medical treatment that a patient or his or her legal representative wants when, in the medical professional’s opinion, the treatment would do little or nothing to benefit the patient. For example, a doctor or hospital might refuse to provide an additional round of chemotherapy to a person with end-stage cancer where it

¹⁵ Letter from 22 organizations, to Roger Severino, Director, U.S. Dep’t of Health and Human Servs., Office for Civil Rights and Lance Roberson, Administrator and Assistant Secretary for Aging, Administration on Community Living (July 10, 2018). The letter is on file with OCR.

¹⁶ Letter from Matt Valliere, Executive Director, Patients’ Rights’ Action Fund, and Diane Coleman, President and CEO, Not Dead Yet, on behalf of 17 organizations, to Roger Severino, Director, U.S. Dep’t of Health and Human Servs., Office for Civil Rights (May 6, 2019). The letter is on file with OCR.

¹⁷ See, Memorandum from Ronald Newman, Susan Mizner, and Vania Leveille, American Civil Liberties Union, to Roger T. Severino, Director, U.S. Dep’t of Health and Human Servs., Office for Civil Rights (Sept. 3, 2019). The letter is on file with OCR.

is determined to be unlikely to result in any medical benefit to the patient. Futility policies articulate how hospitals and other health care institutions will address these conflicts between physicians and patients (or their families) as to the advisability of continuing what a clinician deems to be “futile care.”

Because a determination of futility may allow the withdrawal or withholding of life-saving or life-sustaining treatment over the objection of an individual or their family, this area is highly contentious – and a significant risk of discrimination exists for individuals with disabilities. Futility determinations are typically made in one of two categories:

1) Determinations of quantitative futility, under which a treatment is considered overwhelmingly unlikely to offer any clinical benefit, and

2) Determinations of qualitative futility, under which a treatment is considered likely to offer clinical benefit, but the patient’s anticipated quality of life after treatment is considered too low to justify the treatment.

The Department recognizes the permissibility of quantitative futility determinations, although it notes the importance of careful monitoring to ensure that determinations of quantitative futility are not a cover for discrimination. However, the Department believes that *qualitative* futility determinations on the basis of disability status, contrary to the wishes of the patient (or the patient’s family), may constitute disability discrimination under Section 504. Descriptions of qualitative futility determinations in the medical literature often explicitly incorporate factors that are discriminatory. A key article from 1990, that remains a frequently cited article in the field, proposed an approach to qualitative futility, stated in part:

Some qualitatively poor results should indeed be the patient's option, and the patient should know that they may be attainable. We believe, however, that other sorts of qualitatively poor results fall outside the range of the patient's autonomy and need not be offered as options.... Qualitatively poor results [include]... conditions requiring constant monitoring, ventilatory support, and intensive care nursing....¹⁸

Elsewhere, the authors propose that if a treatment “cannot end dependence on intensive medical care, the treatment should be considered futile.”¹⁹ Many people with disabilities require these kinds of supports, often on a long-term basis, in order to survive and thrive. With such supports, individuals with disabilities can live many years, enjoying meaningful social, family and professional relationships. Physician or hospital determinations that an individual with a disability’s life is not worth living on the basis of the individual’s dependence on others or need for ventilator support, intensive care nursing, tracheotomy or other ongoing medical care needs can constitute discrimination on the basis of disability under Section 504.

OCR is interested in information on how stereotypes or bias about the quality of life of an individual with a disability or individuals with certain types of disabilities generally may inappropriately influence decisions about appropriate medical care or the futility of certain medical care for an individual with a disability. We are interested in information on whether and under what circumstances the consideration of the present or anticipated disability of a qualified individual may be the basis of medical decision-making in the consideration of the withdrawal, denial, or delay of life-saving or life-sustaining care for the individual and what definition is appropriate for ascertaining when an individual with a disability is considered qualified in such circumstances. OCR

¹⁸ Schneiderman LJ, Jecker NS, Jonsen AR. Medical Futility: Its Meaning and Ethical Implications. *Ann Intern Med.* 1990;112:949–954.doi: 10.7326/0003-4819-112-12-949.

¹⁹ *Id.*

recognizes that there are circumstances when a person's disability may render them unqualified to receive certain forms of care, as it would be exceedingly unlikely to be effective (i.e: circumstances of quantitative futility). Furthermore, OCR does not believe that disability rights law creates any obligation to interfere with the right of a patient with a disability or their legal representative to choose to decline treatment, but rather seeks information on the appropriateness of the withdrawal of, or failure to provide, life-saving or life-sustaining care by a covered entity against the wishes of the patient or their legal representative, particularly when based on a judgment of a patient's quality or relative worth of life, a belief or assessment that an individual does or would impose a burden on caregivers or society based on disability or stereotypes or bias based on disability, whether assessed based on the individual's status prior to receiving life-sustaining or life-saving care or anticipated status after receiving such care. We are also seeking information on the extent to which decisions regarding whether to withdraw, deny or delay life-saving or life-sustaining care for an individual with a disability are currently based on an individualized assessment of whether such action is medically appropriate, based on reasonable judgment that relies on current medical knowledge or on the best available objective evidence. We seek information on the extent to which this is already the case, what costs or benefits might be associated with any requirement that this be the case, and the impact of requiring that such individualized assessment not include as a factor judgments regarding quality of life or relative worth based on disability, whether assessed based on the individual's status prior to treatment or anticipated status afterwards.

We seek information on disability discrimination in actions to withdraw, deny, or delay life-sustaining or life-saving healthcare or health services, including ventilators, dialysis machines, hydration, medicines, antibiotics, and feeding tubes, or to fail to offer or refer for or provide access to such healthcare or health services. We also seek information on disability discrimination in actions to develop, establish, adopt, disseminate, or implement a policy denying or withdrawing life-sustaining or life-saving care on the basis of disability or actions to steer, encourage, pressure, or unduly influence the patient with a disability or his or her legal representative to decline or withhold consent for the provision of life-sustaining or life-saving care, to consent to the withdrawal of life-sustaining or life-saving care, or to consent to the provision or receipt of any life-ending item or service. We seek information on disability discrimination in actions to require, steer, encourage, pressure or unduly influence an individual with a disability or his or her legal representative to make advanced care planning decisions to withdraw or withhold life-sustaining or life-saving care, including in order to continue to receive services. We also request information as to whether there are other instances of potential discrimination in the life-saving or life-sustaining care context that OCR should consider specifically addressing.

For example, a patient that has late stage Alzheimer's disease has developed pneumonia and is in need of a respirator to provide assistance breathing. Her husband has requested that physicians start her on a respirator, consistent with what he believes would be his wife's wishes. Although the attending physician normally would start respirator support for a patient with pneumonia who needed assistance breathing, he tells the patient and her husband that the patient should not receive respirator support, given the poor

quality of life that doctor believes the patient has, and declines to put the patient on the respirator. OCR seeks information on if, under such circumstances, the doctor has discriminated on the basis of disability in denying the patient access to respirator support based on stereotypical perceptions of her disability and value judgments regarding the patient's quality of life arising from their disability.

Similarly, a teenage boy with intellectual and developmental disabilities develops periodic treatable respiratory infections and pneumonia due to a chronic condition. His parents seek medical care for this treatable condition. Judging his quality of life to be poor due to cognitive and communication disabilities, the health care provider decides to withhold antibiotics and other medical care when he next falls ill. Instead, the provider refers him to hospice care, and declines to provide life-sustaining treatment. The provider makes this decision not because she anticipates that care would be ineffective, but because she determines that such care would be effective at prolonging the patient's life and that the patient's life would not be worth living on the basis of disability. OCR seeks information on whether, under such circumstances, the provider has discriminated on the basis of disability.

Similarly, a patient seeks treatment for a severe respiratory infection that is anticipated to cause long-term disabilities even among some previously healthy patients. After reviewing the patient's case, her physician concludes that she will likely require use of a ventilator on a chronic basis in the event that she does survive treatment. Judging this to be a qualitatively poor outcome, the physician refuses to provide treatment, concluding that care is qualitatively futile despite a reasonable likelihood that it would succeed in

prolonging the patient’s life. OCR seeks information on whether, under such circumstances, the provider has discriminated on the basis of disability.

OCR does not have robust data showing how often circumstances arise involving the withdrawal or withholding of life-sustaining care for a person with a disability. OCR seeks information, whether scholarly studies, analytical reports, or other evidence of these circumstances as well as stakeholder feedback and individual experiences on all aspects of this issue, including both the frequency of withdrawal or withholding of life-saving or life-sustaining care from people with disabilities and the frequency of doing so based on potentially discriminatory rationales.

In addition to medical futility policies, OCR has learned through communications from advocacy organizations, media reports and investigations that some individuals with disabilities face discrimination through the imposition of involuntary “Do Not Resuscitate Orders” (“DNR”). A DNR is a common medical order, written on the patients’ medical file and hospital chart, by a physician after speaking with the patient, the holder of the patient’s healthcare proxy, or the patient’s family, and is set up before an emergency occurs. It instructs healthcare providers caring for the patient with the critical information not to provide cardiopulmonary resuscitation (“CPR”) if the patient stops breathing or if the patient's heart stops beating. The DNR conveys that the patient, the patient’s guardian or the person holding the patient’s medical power of attorney has consented to the DNR, and it is specifically and only about CPR and does not apply to other treatments, such as pain medicine, other medicines, or nutrition.²⁰ There are a number of well-known cases of involuntary DNRs imposed on children whose parents

²⁰ See MedlinePlus “Do-Not-Resuscitate Order,” (Review Date January 12, 2020), <https://medlineplus.gov/ency/patientinstructions/000473.htm>.

were present at the hospital and yet unaware of the DNR. In the United States, one such case has served as the impetus for passing state laws, now known as Simon's Laws.

Simon's Laws are intended to protect minor children from being subject to DNR orders unbeknownst to the parents who are often present in the hospital but not consulted nor asked to sign DNR orders for their children.²¹

Simon Crosier was born in a Missouri hospital on September 7, 2010. He was diagnosed with the chromosomal disorder Trisomy 18, and died on Dec. 3, 2010, three days before his scheduled heart surgery.²² Simon's parents later discovered a DNR order in his medical file to which they had not consented. His parents stated that "it explained why the medical professionals stood around and did nothing as [they] begged the doctors to help Simon and were told that they could not do anything." Simon's parents and other parents note that if Simon had not been labeled with the disability of chromosomal abnormality, the hospital staff would have been obligated to do all that they could to save the life of Simon. Even with a DNR order, which does not preclude medicine or food and water, they chose to deny nutrition to Simon, providing him only comfort food consisting of drops of sucrose, otherwise known as sugar water. If Simon had not stopped breathing, he might have starved to death because he was labeled with an allegedly futile disabling condition and therefore denied all medical treatment.

In some of these situations, physicians, and not the patient, parents, or health care proxy holder, make decisions based on the physician's personal views and whether a

²¹ The following states have passed legislation known as "Simon's Law": Kansas (SB 85) (2017), Arizona (HB 2122) (2019), Missouri (HB 138) (2019), South Dakota (HB 1055) (2019), Idaho (HB 578) (2020), and Iowa (HF 594) (2020).

²² See Global Genes "Simon's Law: Who Decides?", <https://globalgenes.org/2014/12/18/simons-law-decides/>.

patient's situation is considered "medically futile" or the physician views the patient to have lesser "quality of life" than they themselves would want to endure. Decisions may vary drastically regarding the burdens and benefits of specific interventions. It has become clear that the issues of "medical futility" and "quality of life" are highly subjective and what may be deemed futile by one physician may not be deemed futile by another doctor, or by patients and their guardians.

As such, we seek information on the issuance of involuntary DNR orders, which are DNRs that are entered into medical charts without the permission of the patient, the parents of a minor, legal guardian, or health care proxy holder. OCR is concerned that such orders may represent a serious risk of discrimination against individuals with disabilities, particularly when patients or their authorized representatives are not aware of them. We seek information on the impact of requiring that covered entities provide notice to the patient or the patient's legal representative prior to implementing the withdrawal or withholding of life-sustaining care or entering a DNR, where such actions are not requested or consented to by the patient or the patient's legal representative.

In addition, OCR is concerned by media reports of inappropriate steering of patients with disabilities or their family members to decline life-saving or life-sustaining care or to consent to the withdrawal of life-saving or life-sustaining care.²³ In some cases, patients with disabilities with routine illnesses are pressured by their physicians to not be resuscitated, against their desires and wishes.²⁴ For example, a 2012 report from the

²³ Joseph Shapiro, "As Hospitals Fear Being Overwhelmed By COVID-19, Do The Disabled Get The Same Access?" *NPR* (Dec. 14, 2020), <https://www.npr.org/2020/12/14/945056176/as-hospitals-fear-being-overwhelmed-by-covid-19-do-the-disabled-get-the-same-acc>.

²⁴ Lauren Drake, "New Oregon Law Bars Discrimination Against People With Disabilities During Pandemic," *OPB*, (July 11, 2020), <https://www.opb.org/news/article/law-bars-disability-discrimination-covid-19/>.

National Disability Rights Network documented multiple instances of providers steering individuals with disabilities or their family members to agree to decline life-saving or life-sustaining care or to consent to the withdrawal of life-sustaining care. In one instance, family members reported that the patient's doctor informed them that their relative - a 72-year old patient with a developmental disability - would have poor quality of life and that life-sustaining treatment should no longer be provided. Though initially consenting to the withdrawal of treatment, the family experienced pressure from the clinician when attempting to restore treatment and nutrition.²⁵ The recent case of Sarah McSweeney, documented as part of a National Public Radio (NPR) investigation into multiple reports of alleged health care discrimination against individuals with disabilities involving pressure to agree to the withdrawing or withholding of life-saving or life-sustaining care, offers one such example. Ms. McSweeney was a 45-year old woman with multiple disabilities. She was brought to the hospital due to concerns that she may have contracted COVID-19. Shortly after arriving, her guardian received a call from the hospital expressing puzzlement as to why her Physician Orders for Life-Sustaining Treatment (POLST) form indicated that Ms. McSweeney should receive life-sustaining treatment in the event that she required it. Over the next several weeks, hospital personnel pressured Ms. McSweeney's guardian to consent to the withdrawal or withholding of life-sustaining care, often expressing skepticism that a person whose disabilities precluded mobility and speech could be considered to have quality of life. Ultimately, Ms. McSweeney died of sepsis due to aspiration pneumonia, a typically treatable

²⁵ National Disability Rights Network, "Devaluing People with Disabilities: Medical Procedures that Violate Civil Rights," (May 2012), <https://www.ndrn.org/wp-content/uploads/2012/05/Devaluing-People-with-Disabilities.pdf>.

condition. Her case and others like it prompted the passage of a new law by the Oregon legislature prohibiting hospitals from conditioning admission or treatment, or suggesting that treatment is conditioned, on a patient having POLST or executing advance directive or other instruction regarding administration, withholding or withdrawing of life-sustaining procedures or artificially administered nutrition and hydration.

When people with disabilities are devalued and they or their legal representatives are subject to pressure to agree to decline life-saving or life-sustaining treatment, there can be deadly consequences. In some cases, patients can speak for themselves and convince the doctor that they do indeed want to live and request they be resuscitated if, for example, their heart should stop during a surgery. In others, they may not be able to communicate their desires or they may not be acknowledged or respected. The impropriety of such pressure is exacerbated by the power differential between vulnerable patients (especially those with disabilities) and treating physicians. These situations endanger the autonomy of patients with disabilities through pressuring of patients with disabilities to make decisions regarding treatment or advanced care planning based on quality of life assumptions or discriminatory stereotypes.

OCR is also seeking information on how common it is for a provider to engage in steering, encouraging, pressuring, or unduly influencing a patient with a disability or his or her legal representative to decline or withhold consent for the provision of life-sustaining or life-saving care or to consent to the withdrawal of life-sustaining or life-saving care. OCR also seeks comment on appropriate definitions for these terms in different contexts.

ISSUE 3: Suicide Prevention and Treatment

The CDC reports that suicide is a large and growing public health problem and is now the tenth leading cause of death in the United States. Suicide was responsible for more than 48,000 deaths in 2018. In addition, the CDC reports that, in 2018, 10.7 million American adults seriously thought about suicide, 3.3 million made a plan, and 1.4 million attempted suicide.²⁶

OCR has reason to believe that suicide disproportionately affects individuals with disabilities and veterans. For example, one in 20 Americans with schizophrenia die by suicide and Americans with mood disorders, like depression or bipolar disorder, die by suicide at a rate 25 times the general population.

Further, the NCD has reported that a double standard exists in suicide prevention efforts where people with disabilities are not referred for mental health treatment when seeking assisted suicide, while people without disabilities do receive such referrals. The NCD recommended that the Department issue a regulation requiring nondiscrimination in suicide prevention services which would state that physicians must treat a request for assisted suicide or any other form of hastened death the same, regardless of whether or not the patient has a disability.

Disability organizations have raised particular concerns about discrimination in the disparate consideration of individuals with disabilities for the provision of or referral to suicide prevention services, compared to others. In its report, *The Danger of Assisted Suicide Laws*, NCD found that concerns of disability discrimination have been

²⁶ Centers for Disease Control and Prevention, "Violence Prevention - Preventing Suicide," <https://www.cdc.gov/violenceprevention/suicide/fastfact.html>.

heightened in recent years with the greater availability of suicide assistance services in some areas.

The Department is concerned that there may be a double standard in which doctors disproportionately facilitate assisted suicide for individuals with disabilities and refer for suicide prevention or psychological treatment for patients without disabilities. Oregon became the first state in the country to enact an assisted suicide law, which became effective in 1997.²⁷ Since then, New Jersey, California, Colorado, Hawaii, Vermont, Washington, Maine, and the District of Columbia have passed similar legislation.²⁸ The May 6, 2019 letter from 17 disability advocates raised strong concerns about these assisted suicide laws:

The public image of severe disability as a fate worse than death has become grounds for carving out an exception to longstanding laws and public policies about suicide intervention services. Legalizing assisted suicide means that some people who say they want to die receive suicide prevention services, while others receive assistance to die.²⁹

In their publication, “A Primer on Assisted Suicide Laws,” the Patients’ Rights Action Fund and the Disability Rights Education and Defense Fund highlight key objections to assisted suicide, the insufficiency of safeguards, and instances of abuse of vulnerable individuals in this context.³⁰

Not Dead Yet, a national, grassroots disability rights group that opposes legalization of assisted suicide and euthanasia as forms of disability discrimination,

²⁷ Oregon Revised Statutes, 27.800-995.

²⁸ See Marina Villeneuve, “Maine Becomes Eighth State To Legalize Assisted Suicide,” (June 12, 2019), <https://www.apnews.com/7f0fe9d789294a02852c1669c892f382>.

²⁹ Letter from Matt Valliere, Executive Director, Patients’ Rights’ Action Fund, and Diane Coleman, President and CEO, Not Dead Yet, on behalf of 17 organizations, to Roger Severino, Director, U.S. Dep’t of Health and Human Servs., Office for Civil Rights (May 6, 2019).

³⁰ Patients’ Rights Action Fund and Disability Rights Education and Defense Fund, *A Primer on Assisted Suicide Laws* (July 2017), <https://patientsrightsaction.org/wp-content/uploads/2017/07/Final-Primer.pdf>.

writes that there is “an established body of research demonstrating that physicians underrate the quality of life of people with disabilities compared with our assessments.”³¹

Diane Coleman, President and Chief Executive Officer of Not Dead Yet, states:

“Legalized assisted suicide sets up a double standard: some people get suicide prevention while others get suicide assistance, and the difference between the two groups is the health status of the individual.”³²

In its Position Statement on Assisted Suicide, The Arc, the largest national organization advocating for, and providing community-based services to, individuals with intellectual and developmental disabilities and their families, noted their main objections to assisted suicide for individuals with intellectual disabilities:

- The documented history of denial of basic rights and medical care, including nutrition and hydration, places the lives of individuals with intellectual disabilities at extraordinary risk.
- Despite well-intended laws designed to protect individuals with intellectual disabilities, such individuals can be unduly influenced by authority figures such as doctors, healthcare workers, social workers, family, guardian/conservators, and friends, resulting in a lack of true informed consent.
- The current system of health care services, particularly managed care, provides economic incentives for rationing healthcare, and can lead to the encouragement of physician-assisted suicide.
- Society often incorrectly perceives that individuals with intellectual disabilities, by definition, have a poor quality of life.³³

³¹ Not Dead Yet, “Not Dead Yet Disability Activists Oppose Assisted Suicide As a Deadly Form of Discrimination,” <https://notdeadyet.org/assisted-suicide-talking-points>, citing K.A. Gerhart, J. Kozoil-McLain, S.R. Lowenstein, & G.G. Whiteneck, “Quality of Life Following Spinal Cord Injury: Knowledge and Attitudes of Emergency Care Providers.” *Annals of Emergency Medicine*, 23, 807-12 (1994); L.A. Cushman and M.P. Dijkers, “Depressed Mood in Spinal Cord Injured Patients: Staff Perceptions and Patient Realities,” 71 *Archives of Physical Medicine and Rehabilitation* 191-96 (1990).

³² *Id.*

³³ The Arc, “Physician-Assisted Suicide, Position Statements,” https://www.thearc.org/file/16-117-The-Arcs-Position-Statements_B7_Physician-Assisted-Suicide.pdf.

Marilyn Golden, Senior Policy Analyst at the Disability Rights Education and Defense Fund, provides a perspective that highlights the risk of assisted suicide for vulnerable populations:

Contrary to the claims of its supporters, it would radically decrease, not increase, individual self-determination, due to the significant risk of abuse. It poses substantial danger to people with disabilities and many other people in vulnerable circumstances. For example, people with psychiatric disabilities and depression are given lethal drugs in Oregon, despite the claims of proponents that these conditions disqualify a person. Elder abuse is a growing but still largely unreported reality that threatens to pressure seniors toward an early death.³⁴

To understand how best to address these issues, OCR seeks information from the public and stakeholders. OCR is specifically interested in the prevalence of actions by providers to steer, encourage, pressure or unduly influence a qualified individual with a disability to suicide assistance services based on the individual's disability. We also seek information on disability discrimination in psychological or psychiatric treatment, assessments or referrals under standards of care governing the treatment of persons with suicidal ideation or depression and through failures to refer an individual with a disability to suicide prevention services, or delay or failure to provide suicide prevention services on the basis of the individual's disability.

³⁴ Marilyn Golden, Senior Policy Analyst at the Disability Rights Education and Defense Fund, "Not Dead Yet leaflet," <https://dredf.org/wp-content/uploads/2012/08/NDY-disability-flyer.pdf>. In "Death with Dignity": A Recipe for Elder Abuse and Homicide (Albeit Not by Name), 11, no. 2 *Marquette Elder's Advisor* 387-401 (Spring 2010), Margaret K. Dore discusses shortcomings in assisted suicide legislation, including the lack of a requirement that the patient be competent at the time of taking the medication and the possibility that someone other than the patient could administer the medication. She asserts that these and other shortcomings create the possibility for elder abuse, patient coercion, or even involuntary homicide. Lara Schwartz echoes a similar concern that physician-assisted suicide laws do not expand, but instead limit, end-of-life choices. For example, she writes, they do not guarantee access to alternatives such as palliative or hospice care, and may actually encourage those with disabilities to end their lives rather than pursue more expensive life-prolonging options. Lara Schwartz, 3, no. 1 *Advocates of Dignity Can Do Better than Death*, Savannah Law Review 185-206 (2016). Schwartz believes that death with dignity laws "equate disability with indignity." *Id.* at 197.

We request information on the nature and extent of disability discrimination in this area, including any research or statistical information. We would also welcome descriptions of specific instances where individuals with disabilities related to anxiety, depression, other psychological conditions, or physical or developmental disabilities, have expressed suicidal ideation or desire to harm themselves, but were not provided referrals for psychological assistance or were steered toward assisted suicide in those States that allow it, instead of suicide prevention services. While we welcome individual experiences and personal stories, we would be appreciative of any studies, scholarly reports, or other information sources on these subjects.

ISSUE 4: Crisis Standards of Care

During the COVID-19 pandemic, Congress, Federal agencies, advocates, the media, and members of the public have sent communications and complaints to OCR raising concerns about the potential for discrimination on the basis of disability in the allocation of health care resources in a time of crisis, alleging that state Crisis Standards of Care guidelines included discriminatory provisions.³⁵ OCR has resolved civil rights

³⁵ On March 25, 2020, a bipartisan bicameral Congressional coalition sent Secretary Azar and Attorney General Barr a letter asking HHS to notify states of their civil rights obligations as they review and develop their crisis standards of care (“CSCs”). *See* “U.S. Senator James Lankford, “Lankford, Gillibrand Lead Bipartisan, Bicameral Call to Protect Civil Rights for People with Disabilities Amidst COVID-19 Pandemic” (Mar. 25, 2020), <https://www.lankford.senate.gov/news/press-releases/lankford-gillibrand-lead-bipartisan-bicameral-call-to-protect-civil-rights-for-people-with-disabilities-amidst-covid-19-pandemic->. This call followed an earlier letter to OCR by NCD, asking for similar guidance. *See* National Council on Disability, “NCD COVID-19 Letter to HHS OCR,” (Mar. 18, 2020), <https://www.ncd.gov/publications/2020/ncd-covid-19-letter-hhs-ocr>. Since the NCD letter, a variety of national organizations representing broad-based constituents have reached out to OCR with similar requests, including the Consortium on Citizens with Disabilities, Cystic Fibrosis Research, Inc., the Disability Rights Education and Defense Fund, the National Disability Rights Network, National Right to Life, and others.

complaints against Alabama, Pennsylvania, Tennessee, and Utah regarding their triage and ventilator allocation guidelines. Disability discrimination during the pandemic is a matter of pressing national concern. The nondiscriminatory allocation of scarce treatment resources and the full enforcement of civil rights laws in the midst of a public health emergency are essential components of public trust in our country's healthcare system. Where individuals with disabilities have reason to believe that they will be discriminated against in the allocation of care, they may be less likely to seek treatment.

OCR is concerned that multiple states have or had ventilator rationing guidelines that might discriminate against individuals with disabilities. The Department is concerned that many Crisis Standards of Care plans still use allocation criteria, such as resource-intensity or long-term survival, that may discriminate on the basis of disability by screening out individuals with disabilities without sufficient justification. Complainants to OCR have also alleged that some Crisis Standards of Care plans allow for the reallocation of scarce resources such as ventilators based on impermissible criteria.

Existing research indicates that many state and provider Crisis Standards of Care plans incorporate criteria that screen out individuals with disabilities.³⁶ At the same time, significant evidence supports the conclusion that such criteria are not necessary for the provision of health care during a crisis in which resources are scarce.³⁷ On December 18,

³⁶ Manchanda, E. C. C., Sanky, C., & Appel, J. M., "Crisis Standards of Care in the USA: A Systematic Review and Implications for Equity Amidst COVID-19." *Journal of Racial and Ethnic Health Disparities*, 1-13. (2020); Hantel, A., Marron, J. M., Casey, M., Kurtz, S., Magnavita, E., & Abel, G. A. (2020). Piscitello, G. M., Kapania, E. M., Miller, W. D., Rojas, J. C., Siegler, M., & Parker, W. F., "US State Government Crisis Standards of Care Guidelines: Implications for Patients with Cancer." *JAMA Oncology*; (2020). Gina M. Piscitello, MD; Esha M. Kapania, MD; William D. Miller, MD, Variation in Ventilator Allocation Guidelines by US State During the Coronavirus Disease 2019 Pandemic: A Systematic Review. *JAMA Netw Open*, 3(6), e2012606-e2012606.

³⁷ Auriemma, C. L., Molinero, A. M., Houtrow, A. J., Persad, G., White, D. B., & Halpern, S. D., "Eliminating Categorical Exclusion Criteria in Crisis Standards of Care Frameworks." *The American Journal of Bioethics*, 1-9 (2020).

2020, the National Academy of Medicine, the American Medical Association, the American Nurses Association and five other national professional organizations in medicine issued a joint statement regarding Crisis Standards of Care indicating that resource allocation decisions should be made “based on individualized assessments of each patient, using the best available objective medical evidence concerning likelihood of death prior to or imminently after hospital discharge” and that “such assessments should NOT use categorical exclusion criteria on the basis of disability or age; judgments as to long-term life expectancy; evaluations of the relative worth of life, including through quality of life judgments, and should NOT deprioritize persons on the basis of disability or age because they may consume more treatment resources or require auxiliary aids or supports.”³⁸ Such statements from major professional organizations provide persuasive reason to believe such criteria are not necessary for the effective provision of health care even under conditions of resource scarcity.

A growing number of states are also removing such criteria from their Crisis Standards of Care policies, reflecting the recognition that their use is not necessary. For example, the state of Alabama removed from its Crisis Standards of Care plan categorical exclusions on the basis of disability, including one that allowed denying ventilator services to individuals based on the presence of intellectual disabilities, after receiving complaints from disability advocacy organizations and inquiries from OCR.³⁹ In another recent early case resolution, the state of Utah: removed language permitting use of a

³⁸ National Academy of Medicine, “National Organizations Call for Action to Implement Crisis Standards of Care During COVID-19 Surge,” (Dec. 18, 2020), <https://nam.edu/national-organizations-call-for-action-to-implement-crisis-standards-of-care-during-covid-19-surge/>.

³⁹ Dep’t of Health and Human Servs., “OCR Reaches Early Case Resolution With Alabama After It Removes Discriminatory Ventilator Triaging Guidelines” (April 8, 2020), <https://www.hhs.gov/about/news/2020/04/08/ocr-reaches-early-case-resolution-alabama-after-it-removes-discriminatory-ventilator-triaging.html>.

patient’s long-term life expectancy as a factor in the allocation of scarce medical resources; eliminated categorical exclusion criteria on the basis of disability and instead require an individualized assessment based on the best available objective medical evidence; rescinded resource-intensity and duration of need as criteria for the allocation of scarce medical resources; provided reasonable modifications to the use of the state’s primary instrument for assessing the likelihood of short-term survival; incorporated new protections against providers “steering” patients into agreeing to the withdrawal or withholding of life-sustaining treatment; and incorporated language stating that hospitals should not re-allocate personal ventilators brought by a patient to an acute care facility.⁴⁰ Many of these same provisions were also included in Tennessee’s recent changes to their Crisis Standards of Care plan.⁴¹

We seek information on the standards reflected within the NAM statement regarding crisis standards of care, including with respect to NAM’s recommendation against the use of resource-intensity and long-term survival judgments as a basis of allocating care. We also seek information on the nature and types of reasonable modifications necessary for individuals with disabilities within Crisis Standards of Care plans, including to clinical instruments used to assess short-term survival. We also seek information on appropriate protections against providers “steering” patients into agreeing to the withdrawal or withholding of life-sustaining treatment under crisis standards of

⁴⁰ Dep’t of Health and Human Servs., “OCR Resolves Complaint with Utah After it Revised Crisis Standards of Care to Protect Against Age and Disability Discrimination” (August 20, 2020), <https://www.hhs.gov/about/news/2020/08/20/ocr-resolves-complaint-with-utah-after-revised-crisis-standards-of-care-to-protect-against-age-disability-discrimination.html>.

⁴¹ Dep’t of Health and Human Servs., “OCR Resolves Complaint with Tennessee After it Revises its Triage Plans to Protect Against Disability Discrimination” (June 26, 2020), <https://www.hhs.gov/about/news/2020/06/26/ocr-resolves-complaint-tennessee-after-it-revises-its-triage-plans-protect-against-disability.html>.

care and on the issue of re-allocation of ventilators, appropriate standards to apply to such re-allocation decisions under civil rights law and the issue of personal ventilators brought by a patient to an acute care facility.

OCR seeks information on the cost to states of revising state Crisis Standards of Care policies. We anticipate that, should OCR provide regulatory clarity regarding obligations under Federal disability rights law with respect to Crisis Standards of Care, many of the remaining states that have yet to issue Crisis Standards of Care will do so. We solicit information on the accuracy of this assessment. OCR also solicits information on provider and individual patient experiences with unfavorable treatment that might constitute disability discrimination in Crisis Standards of Care, as well as the costs and benefits associated with different potential approaches regarding Crisis Standards of Care, including those articulated by NAM. While we welcome individual experiences and personal stories, we would particularly appreciate any studies, scholarly reports, or other information sources on these subjects. Finally, OCR seeks information on other aspects of unfavorable treatment that might constitute disability discrimination related to Crisis Standards of Care.

ISSUE 5: Health Care Value Assessment Methodologies

Payers often rely on value assessment in order to make decisions regarding coverage, cost, utilization management and other decisions with serious implications for healthcare affordability and accessibility for individuals with disabilities. It is, thus,

important that payers rely only on measures that are nondiscriminatory and do not violate the obligations of federal disability rights law.

To address this, OCR seeks information and feedback concerning the possibility of regulating the use of value assessment methodologies used to determine or inform eligibility for, or the provision or withdrawal of, any item, good, benefit, service, referral or resource under any health care program or activity receiving federal financial assistance, including the terms or conditions making such resources or services available, including whether OCR should consider a prohibition on the use of measures, assessments or tools that discounts the absolute or relative value of a life on the basis of disability, including measures that assign percentage values to the lives of individuals or groups of individuals with disabilities due to their disability or based on judgments regarding quality or relative worth of life associated with disability. We solicit information on the frequency with which such methods are utilized by payers and other covered entities in decisions on eligibility for, or provision or withdrawal of, any item, good, benefit, service, referral or resource under any health care program or activity receiving federal financial assistance, including decisions regarding utilization management, formulary placement, and drug utilization review. We further solicit information on potential alternatives to measures that discount the absolute or relative value of a life on the basis of disability.

ISSUE 6: Children, Parents and Prospective Parents with Disabilities in the Child Welfare System

OCR continues to receive numerous complaints alleging discrimination against parents and prospective parents with disabilities involved with the child welfare system. In the course of its civil rights enforcement activities in the last several years, OCR has found child welfare agencies to have discriminated on the basis of disability against individual parents with disabilities and prospective parents with disabilities.

OCR has received, on an ongoing basis, numerous complaints alleging discrimination against parents and prospective parents with disabilities involved with the child welfare system.⁴² In the last 10 years, OCR has received dozens of such complaints. In the course of its civil rights enforcement activities, OCR has found that child welfare agencies have discriminated on the basis of disability against individual parents with disabilities and prospective parents with disabilities. In addition, OCR has found that child welfare agencies have implemented policies, practices, and procedures that discriminate against parents with disabilities and prospective foster or adoptive parents with disabilities. OCR is also aware of class action lawsuits alleging the practice of placing of foster children with disabilities in hotels and institutional settings, and holding them in psychiatric institutions beyond medical necessity.⁴³

In a recent case, OCR investigated allegations involving Oregon's removal of two infant children from a mother and father with intellectual disabilities after news reports

⁴² Between 2016 and 2020, OCR has received approximately 300 complaints alleging violations under Section 504 in the child welfare system. Because this figure is based on self-reported allegations in complaints, many of which have not been fully investigated, they should, therefore, not be used to imply that complaints are equivalent to violations or that they will otherwise prove meritorious if investigated.

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See Golbert et al. v. Walker et al., No.1:18-cv-08176-JZL (N.D. Ill.) (2018); *A.R. v. State of Oregon*, No. 3:16-cv-01895 (D. Or.) (2016); *Wyatt B. v. Brown*, No. 6:19-cv-00556-AA (D. Or.) (2019); *Jonathan R. et al. v. Justice et al.*, No. 3:19-cv-00710 (S.D.W. Va.) (2019); *B.K et al. v Faust et al*, No.1 cv-15-00185-PHX (D. Az.)(2020).

alleged the removal was based in significant part on their Intelligent Quotient (IQ) scores. OCR's investigation identified systemic deficiencies in the state child welfare agency's implementation of its disability rights program to prevent discrimination against parents with disabilities in the child welfare system.⁴⁴

Most recently, OCR investigated a complaint filed by an aunt and uncle who sought to adopt their young niece and nephew who were in the custody of West Virginia's Bureau of Children and Families Programs (BCF).⁴⁵ The aunt and uncle allege BCF denied their request for placement of the children based on the uncle's being in recovery from opioid use disorder and his long-term use of physician-prescribed Suboxone as part of his medication-assisted treatment program. The relatives also allege BCF declined to provide the aunt and uncle the opportunity to serve as a kinship placement option for these children, although the aunt would have been the primary caregiver, and although the uncle had not tested positive for illegal use of drugs during the course of his treatment (and eventually ceased using Suboxone altogether). Following data requests and witness interviews, OCR identified systemic deficiencies regarding West Virginia's implementation of its disability rights policies, practices, and procedures to ensure the civil rights of individuals in recovery from OUD in West Virginia's child welfare system. Ultimately, West Virginia agreed to work with OCR to ensure full

⁴⁴ Dep't of Health and Human Servs., "Settlement between the United State Department of Health and Human Services and the State of Oregon Department of Human Services," OCR Transaction No. OCR No. 18-290275, 18-291152, 18-291153 (Nov. 20, 2019), <https://www.hhs.gov/sites/default/files/odhs-vra.pdf>.

⁴⁵ Dep't of Health and Human Servs., "OCR Secures Agreement with West Virginia to Protect Persons in Recovery from Opioid Use Disorder from Discrimination on the Basis of Disability" (May 13, 2020), <https://www.hhs.gov/about/news/2020/05/13/ocr-secures-agreement-west-virginia-protect-persons-recovery-opioid-use-disorder-discrimination-basis-of-disability.html>.

compliance with its federal civil rights obligations and entered into a voluntary resolution agreement.

In 2015, following a joint investigation, OCR and the Department of Justice Civil Rights Division (“DOJ”) determined that the Massachusetts Department of Children and Families engaged in discrimination against a mother with a developmental disability.⁴⁶ OCR and DOJ found that the supports and services provided and made available to non-disabled parents were not provided to this parent, and she was denied reasonable modifications to accommodate her disability. As a result, the family was separated for more than two years. Recently, HHS and DOJ reached an agreement with the state agency to resolve findings that the agency discriminated against parents in the administration of its child welfare programs.⁴⁷

According to a comprehensive 2012 report by NCD, parents with disabilities are overly, and often inappropriately, referred to child welfare services and, once in the child welfare system, are permanently separated from their children at disproportionately high rates.⁴⁸ In a review of research studies and other data, NCD concluded that, among parents with disabilities, parents with intellectual disabilities and parents with psychiatric disabilities face the most discrimination based on stereotypes, lack of individualized assessments, and failure to provide needed services.⁴⁹ Parents who are blind or deaf or who have other physical disabilities also report significant discrimination in the custody

⁴⁶ Letter from the U.S. Department of Justice, Civil Rights Division and U.S. Department of Health and Human Services, Office for Civil Rights to the Massachusetts Department of Children and Families (Jan. 29, 2015), https://www.hhs.gov/sites/default/files/mass_lof.pdf.

⁴⁷ See *ADA.gov*, “Settlement between the U.S. Departments of Justice and Health and Human Services and Massachusetts Department of Children and Families,” (Nov. 19, 2020), https://www.ada.gov/mdcf_sa.html.

⁴⁸ National Council on Disability, “Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children” 14, 18 (2012), www.ncd.gov/publications/2012/Sep272012/.

⁴⁹ *Id.* at 114, 122-26.

process.⁵⁰ In addition, individuals with disabilities seeking to become foster or adoptive parents encounter bias and unnecessary barriers to foster care and adoption placements based on speculation and stereotypes about their parenting abilities.⁵¹ Discriminatory separation of parents from their children can result in long-term negative consequences to both parents and their children. The NCD report discusses several case studies where parents and their children were similarly deprived of the opportunity to bond based on discriminatory actions. The NCD report also examines the use of Intelligence Quotient (IQ) scores to determine a parent's capacity or fitness to safely care for a child. This practice has serious and far-reaching implications for parents with disabilities, particularly parents with intellectual disabilities who experience high rates of removal and loss of child custody.

NCD's report noted the inappropriateness of using IQ tests as a means of assessing parenting ability:

These tests continue to be administered despite the research evidence demonstrating that parental IQ is a poor predictor of parenting competence. When norm referenced assessments are used, (sub)normal may be equated with (in)adequate so that the parenting practices and behaviors of parents with intellectual disability are judged subnormal and inadequate rather than simply different...sole reliance on the IQ, resulting in diagnosis of intellectual disability, leads to states having "bypass" statutes, which allow child removals to occur simply on a categorical or diagnostic basis, without any individualized assessment or observation of parenting. Such categorical removals also occur when parents

⁵⁰ *Id.* at 92-93.

⁵¹ *Id.* at 194-99.

have psychiatric disabilities, although specialists urge individualized assessment and extensive observation of the parent-child relationship when assessing the capability of such parents...Parenting ability is a complex set of variables that cannot be reduced to a simple intelligence test. It is imperative that evaluators asked to determine the parenting capabilities of an individual observe the parent and child together over extended periods of time.⁵²

Discrimination against parents and prospective parents with disabilities has been a significant issue for many years in the child welfare system. In 2015, HHS and DOJ jointly published *Protecting the Rights of Parents and Prospective Parents with Disabilities: Technical Assistance for State and Local Child Welfare Agencies and Courts under Title II of the Americans with Disabilities Act and Section 504 of the Rehabilitation Act*, a technical assistance document to assist state and local child welfare agencies and courts to ensure that the welfare of children and families is protected in a manner that also protects the civil rights of parents and prospective parents with disabilities.⁵³

The issue also has gained the attention of the American Bar Association, which adopted a resolution urging government to enact legislation and implement policies limiting the circumstances when a parent's disability could be a basis for the denial of parental access to his or her child or termination of parental rights, or when a prospective

⁵² *Id.* at 133-134.

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Dep't of Health and Human Servs. & Dep't of Justice, "Protecting the Rights of Parents and Prospective Parents with Disabilities: Technical Assistance for State and Local Child Welfare Agencies and Courts under Title II of the Americans with Disabilities Act and Section 504 of the Rehabilitation Act," (2015), <https://www.hhs.gov/sites/default/files/disability.pdf>.

parent’s disability could be a bar in adoption and foster care.⁵⁴ Concerns about discrimination against parents and prospective parents with disabilities have led 16 states to pass legislation prohibiting such discrimination.⁵⁵ Yet, as noted in a 2019 article appearing in the *Family Court Review*:

The persistent and pervasive bias within the family law system against parents with disabilities is particularly disconcerting because it is largely not grounded in contemporary science. In fact, ‘high-quality studies indicate that disability alone is not a predictor of problems or difficulties in children and that predictors of problem parenting are often found to be the same for disabled and nondisabled parents’ Notably, indeed, some scholars opine that children of parents with disabilities have many favorable outcomes compared to their peers.⁵⁶

OCR is seeks information on various approaches to more clearly apply the nondiscrimination requirements of Section 504 to child welfare programs and activities and to clarify that children with disabilities served by the child welfare system, parents, and prospective adoptive and foster parents are within the class of individuals with disabilities to which Section 504 protections extend. OCR seeks information from the public on the scope of the problem.

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“RESOLVED, That the American Bar Association urges all federal, state, territorial, and tribal governments to enact legislation and implement public policy providing that custody, visitation, and access shall not be denied or restricted, nor shall a child be removed or parental rights be terminated, based on a parent’s disability, absent a showing—supported by clear and convincing evidence—that the disability is causally related to a harm or an imminent risk of harm to the child that cannot be alleviated with appropriate services, supports, and other reasonable modifications. . . . FURTHER RESOLVED, That the American Bar Association urges all federal, state, territorial, and tribal governments to enact legislation and implement public policy providing that a prospective parent’s disability shall not be a bar to adoption or foster care when the adoption or foster care placement is determined to be in the best interest of the child.” See “ABA Policy Resolution 114: Disabled Parents and Custody, Visitation, and Termination of Parental Rights,” *American Bar Association* (Feb. 2017), https://www.americanbar.org/groups/public_interest/child_law/resources/attorneys/disabled-parents-and-custody--visitation--and-termination-of-par/.

⁵⁵ National Research Center for Parents with Disabilities, “Map of Current State Legislation Supporting Parents with Disabilities” (2019), <https://heller.brandeis.edu/parents-with-disabilities/map/index.html>.

⁵⁶ Robyn M. Powell, “Family Law, Parents with Disabilities, and the Americans with Disabilities Act,” 57 *Fam. Ct. Rev* 1 (2019).

OCR seeks information on the impact or desirability of clarifying the requirement for individualized assessment in the child welfare context. Specifically, we seek information on the appropriateness and impact of requiring child welfare authorities to perform individualized assessments to consider a parent or prospective parent's ability to care for a child beyond simply identifying a disability, potentially drawing from a wealth of sources including interviews, observations, and medical and social history, and seek information on what methods may be appropriate to require providers to use to conduct and document such individualized assessment in child welfare contexts. In addition, OCR seeks information on the appropriateness and effectiveness of requiring that any decision related to removals or visitation for parents or prospective adoptive or foster parents with disabilities must consider whether there is a causal relationship between the parent's disability and the safety of the child that cannot be alleviated with appropriate services, adaptive equipment or reasonable modifications, and whether that safety issue can be mitigated through appropriate auxiliary aids and services or reasonable modifications.

OCR seeks information about relevant methods and sources of information in the context of individualized assessment, and appropriate auxiliary aids and services and reasonable modifications in the child welfare context as well as any examples of how such assessments and modifications will work. OCR also seeks information on methods to reduce the number of children with disabilities and children of parents with disabilities inappropriately placed in foster care, and to increase the number of families, where one member has a disability, remaining together, including with appropriate support and services where needed. We seek input on how best to accomplish these goals.

OCR is also aware of class action lawsuits alleging the practice of placing of foster children with disabilities in hotels and institutional settings, and holding them in psychiatric institutions beyond that required by the medical needs of the child. OCR also seeks information on the compliance of child welfare entities under the most integrated setting requirements of Section 504, particularly with respect to the placement of children with disabilities in foster care and other child welfare contexts. We solicit information on this issue and welcome feedback as we consider more clearly articulating and clarifying the existing obligation of child welfare entities to serve children with disabilities in the most integrated setting. In particular, OCR is interested in relevant examples of unnecessary segregation of children with disabilities within state child welfare systems as well as models of support that child welfare entities have adopted to more effectively serve children with disabilities in the most integrated setting.

ISSUE 7: Auxiliary Aids and Accessible Medical Equipment in the Health Care System

Section 504 and Title II of the Americans with Disabilities Act require that covered health care providers take appropriate steps to ensure that communications with individuals with disabilities are as effective as communications with others in the health care program. Under these requirements, covered entities are obligated to provide appropriate auxiliary aids and services to individuals with disabilities, where necessary to afford such individuals an equal opportunity to the benefit or service in question. Unlike regulations applying to health care providers by the Department of Justice and in the

Department's 1557 regulation, the Department's own section 504 regulation does not articulate specific requirements on this subject. We seek information on whether OCR should take steps to make its Section 504 regulation consistent with the regulations of the Department of Justice under the Americans with Disabilities Act and with the Department's own regulation under Section 1557 of the Affordable Care Act.

In addition, we seek information on the desirability of increasing the number of examples of appropriate auxiliary aids for the health care setting in the regulation. Because we are aware of the difficulties that persons with cognitive, developmental, intellectual, or neurological disabilities often face in the health care context, OCR seeks information on appropriate additions to the list of appropriate auxiliary aids. In particular, we seek information on methods of supported decision-making as an auxiliary aid or service in health care and human services contexts, including the use of a support individual to assist an individual with a disability in communicating, processing information, or making medical decisions and the provision of information in plain language. We seek information on an appropriate definition for supported-decision making and what obligations, if any, OCR should consider articulating with respect to supported decision-making under Section 504. OCR also seeks information on augmentative and alternative communication as an appropriate auxiliary aid, including the purchase or modification of equipment or devices and the provision of assistance or education in their use. We seek information on appropriate methods of augmentative and alternative communication and contexts for its use as an auxiliary aid or service.

In addition, the U.S. Access Board has published standards on what constitutes accessible medical diagnostic equipment. OCR seeks information on the impact of

adopting these standards for hospitals and other health care facilities. We also seek information on if such standards are appropriate for all medical equipment, not just diagnostic medical equipment, and whether any future required standards include appropriate scoping standards (i.e., not just the requirement to have accessible medical equipment, but how many and in what locations).

ISSUE 8: Costs and Administrative Burdens

OCR recognizes the existence of statutory limitations on Section 504, including the requirement that the law does not require covered entities to undertake actions resulting in undue financial or administrative burdens or take any actions that result in a fundamental alteration of its programs or activities. OCR, therefore, seeks public comment and information on any burdens that additional requirements in health care and child welfare may place on entities covered by Section 504.