

Antidiscrimination Protections for People with Disabilities: 2024 Health Care Regulatory Updates

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Introduction

In the spring of 2024, the U.S. Department of Health and Human Services (HHS) updated two rules implementing Section 1557 of the Affordable Care Act (Section 1557)¹ and Section 504 of the Rehabilitation Act of 1973 (Section 504) that will improve access to health coverage and services for people with disabilities.² These rules provide civil rights protections that prohibit discrimination against individuals with disabilities in certain types of health coverage and health care settings. They were issued after extensive public comment, and are well-grounded summaries of the current state of the law, in many cases simply consolidating and organizing long-standing interpretations in one place, and in other places, modernizing the rules to reflect changes in technology.³ While a new administration will take office in January 2025, rules remain in place unless officially rescinded.⁴ Furthermore, the underlying statutes that the rules expound upon cannot be rescinded without an act of Congress. Thus, advocates can and should continue to use these antidiscrimination provisions to ensure that people with disabilities can access the health coverage and care they need.

¹ U.S. Dep't. of Health & Human Servs., *Nondiscrimination in Health Program and Activities*, 42 C.F.R. Parts 438, 440, 457, & 460, 45 C.F.R. Parts 80, 84, 92, 147, 155, &156, 89. Fed. Reg. 37522 (May 6, 2024), https://www.federalregister.gov/documents/2024/05/06/2024-08711/nondiscrimination-in-health-programs-and-

activities#:~:text=The%20Department%20of%20Health%20and%20Human%20Services%20(HHS%20 or%20the,certain%20health%20programs%20and%20activities [hereinafter "Section 1557 rule"].

² U.S. Dep't of Health & Human Servs., *Nondiscrimination on the Basis of Disability in Programs or Activities Receiving Federal Financial Assistance*, 45 C.F.R. Part 84, 89 Fed. Reg 40066 (May 9, 2024), <a href="https://www.federalregister.gov/documents/2024/05/09/2024-09237/nondiscrimination-on-the-basis-of-disability-in-programs-or-activities-receiving-federal-financial [hereinafter "Section 504 rule"].

³ The Section 504 proposed rule received over 5,000 public comments and the Section 1557 proposed rule received over 85,000 public comments.

⁴ 5 U.S.C. § 553.

Background

Section 1557 is the nondiscrimination provision of the Affordable Care Act (ACA).⁵ It prohibits discrimination on the basis of:

- disability;
- race, color, national origin (including limited English proficiency and primary language);
- sex (including pregnancy or related conditions; sexual orientation; gender identity; sex stereotypes; and sex characteristics, including intersex traits);
- age; or
- any combination thereof by incorporating and expanding upon components of preexisting federal civil rights laws.6

Section 1557's provisions apply to health programs and activities receiving federal financial assistance; health programs and activities administered by the executive branch (including Medicare and healthcare.gov); and entities created under the ACA (including the ACA Marketplaces and Qualified Health Plans). The protections of Section 1557 went into effect immediately in 2010, after the law was signed, and the first set of rules to help guide implementation was issued in 2016.⁷ In 2020, however, changes were made by the Trump administration in an attempt to circumvent the statutory nondiscrimination protects and limit the number and types of programs covered by the rule. The updated 1557 rule reinstates key regulatory text that was rescinded by the 2020 rule. It also contains updated language to reflect the current state of the law.

⁵ 42 U.S.C. § 18116.

⁶ Title VI of the Civil Rights Act of 1964, 42 U.S.C. § 2000d et seq.; Title VII of the Civil Rights Act of 1964, 42 U.S.C. § 2000e et seq.; Title IX of the Education Amendments of 1972 20 U.S.C. § 1681 et seq.; Section 504 of the Rehabilitation Act of 1973 29 U.S.C. § 794 et seq.; Age Discrimination Act of 1975, 42 U.S.C. § 6101 et seq.

⁷ U.S. Dep't of Health & Human Servs., *Nondiscrimination in Health Programs and Activities*, Final Rule, 45 C.F.R. Part 92, 81 Fed. Reg. 31376 (May 18, 2016), https://www.federalregister.gov/documents/2016/05/18/2016-11458/nondiscrimination-in-healthprograms-and-activities [hereinafter 2016 1557 Rule].

⁸ U.S. Dep't of Health & Human Servs., Nondiscrimination in Health and Health Education Programs or Activities, Delegation of Authority, 85 Fed. Reg. 37160 (June 19, 2020), https://www.federalregister.gov/documents/2020/06/19/2020-11758/nondiscrimination-in-health-andhealth-education-programs-or-activities-delegation-of-authority [hereinafter 2020 1557 Final Rule].

Section 504 of the Rehabilitation Act of 1973 was the first federal civil rights law designed to protect people with disabilities from discrimination. Section 504 prohibits discrimination on the basis of disability in programs administered by the federal government and all programs that receive federal financial assistance. This includes programs administered by HHS and any program that receives federal funding from HHS. Though the law was enacted in 1973, it took the government nearly four years to issue implementing rules. During that time, enforcement of the law stalled, and there was significant discrepancy in how courts interpreted the law. This delay prompted disability-led demonstrations across the country, demanding strong 504 protections. In 1977, the Department of Health, Education, and Welfare (the precursor to HHS) issued the first set of 504 rules.

Since that time, only minor amendments have been made to the 504 rules, despite significant developments in legislation and case law, including the passage of the Americans with Disabilities Act (ADA), the ACA, and the ADA Amendments Act, as well as the Supreme Court decision in *Olmstead v. L.C.*¹² Additionally, there have been significant advances in technology, communications, medical treatment, assistive devices, and health care systems in the past 47 years. The updated 504 rule is a comprehensive update that reflects these changes and strengthens civil rights protections for people with disabilities in programs and services funded by HHS.

Taken together, Sections 1557 and 504 create a comprehensive matrix of protections against discrimination in health care. While there may be some differences in which entities are covered by which law, the vast majority of health care providers are covered by both. For example, both 1557 and 504 cover medical providers who accept Medicare and Medicaid. Similarly, both rules apply to health insurers and health plans sold in the ACA. Therefore, we discuss the protections in tandem, while making sure to note where the requirements of the

¹¹ See, e.g., Admin. for Cmty. Living, *Final Rule Implementing Section 504 of the Rehabilitation Act of 1973*

⁹ 29 U.S.C. § 794; see also Alison Barkoff, HHS, Admin. for Cmty. Living, *Making Disability Rights History: HHS Announces Powerful Anti-Discrimination Protections* (May 1, 2024), https://acl.gov/news-and79events/acl-blog/making-disability-rights-history-hhs-announces-powerful-anti (noting that "[t]he Rehab Act was the first civil rights legislation protecting disabled people from discrimination.") [hereinafter "ACL 504 Blog"].

¹⁰ ACL 504 Blog.

https://acl.gov/504rule#:~:text=lt%20protects%20people%20with%20all,initial%20504%20regulations%20were%20signed (last visited Oct. 3, 2024).

¹² Americans with Disabilities Act, 42 U.S.C. § 12101 *et seq.*; Patient Protection and Affordable Care Act, 42 U.S.C. 18001 *et. seq.*; Americans with Disabilities Amendments Act, 42 U.S.C. 12101 *et. seq.* (updating the original ADA statute); *Olmstead v. L.C.*, 527 U.S. 581 (1999).

two rules differ. Advocates should take caution, in addressing potential discrimination, to carefully determine which law applies to the entity at issue.

Significant Rule Updates

Below, we outline eight areas where the rules provide updated clarity re non-discrimination and people with disabilities:

- effective communication;
- discriminatory benefit design;
- community integration;
- accessibility of technology;
- decision making support tools;
- medical treatment decisions;
- value assessment tools; and
- accessible medical diagnostic equipment.¹³

A. Effective Communication

Both the Section 1557 Final Rule and the Section 504 Final Rule include updated provisions to ensure that people with disabilities have access to effective communications in health coverage and health care settings. Both rules require covered entities to provide communication for people with disabilities that is equally effective as communications with nondisabled individuals. ¹⁴ In order to do so, both rules require entities to provide access to appropriate auxiliary aides and services such as qualified interpreters, note takers, real-time

¹³ This list does not include all of the significant updates to the rules. For example, for the sake of conciseness and clarity, we left out some of the updated definitions included in both rules. For a more in-depth look at the Section 1557 rule see, Mara Youdelman et al., Nat'l Health Law Prog., *Questions and Answers on the 2024 Final Rule Addressing Nondiscrimination Protections under the ACA's Section 1557* (May 9, 2024), https://healthlaw.org/resource/questions-and-answers-on-the-2024-final-rule-addressing-nondiscrimination-protections-under-the-acas-section-1557/. For a more in-depth explanation of some of the definitions and changes to the Section 504 rule, see Carly Myers et al., Nat'l Health Law Program, *Webinar: Section 504* (May 23, 2004). Additionally, while we focused primarily on the issues around health care coverage and access in this paper, there were important updates around child welfare systems administered by HHS in the Section 504 rule. See 45 C.F.R. § 84.60.

14 45 C.F.R. § 84.77; 45 C.F.R. § 92.202.

captioning, videophones, qualified readers, audio recordings, and Braille materials.¹⁵ Both rules adopt the Americans with Disabilities Act's (ADA) definition of auxiliary aids and services, and both emphasize that the examples included in the rule constitute a non-exhaustive list.¹⁶

In a few instances, language in the two rules is slightly different. Where differences exist, entities covered by both Section 504 and Section 1557 rules must meet both standards. 17 For example, Section 1557 rules were designed to align requirements for communication for people with disabilities with requirements for language access for people with limited English proficiency (LEP).¹⁸ In doing so, the Section 1557 rule states that auxiliary aids and services must be provided free of charge, in accessible formats, in a timely manner, and in such a way to protect the privacy and independence of the individual with a disability. 19 Similarly, the Section 1557 rule aligns the definition of qualified interpreter for a person with a disability with the definition of a qualified interpreter for a person with LEP.²⁰ This includes language, for example, that requires interpreters to adhere to interpreter ethics rules and ensure client confidentiality. In contrast, the Section 504 rule directly adopts its definition of qualified interpreter from ADA Title II regulations.²¹ In the preamble to the 504 rule, HHS specifically clarified that they were choosing to mirror the language in Title II to ensure consistency between the ADA and 504, and noted that where entities were covered by both Section 1557 and Section 504, both definitions of a qualified interpreter would apply without any conflicts.²² Advocates should be ascertain whether an entity is covered by Section 504, Section 1557, or both, and ensure the entity fully meets its obligation with respect to both laws.²³

¹⁵ 45 C.F.R. § 84.10; 45 C.F.R. § 92.4

¹⁶ 28 C.F.R. §§ 35.104, 36.104.

¹⁷ *Id*

¹⁸ 45 C.F.R. § 92.201 (b); see also, e.g., Mara Youdelman, Nat'l Health Law Program, *What is Required Under Title VI and Section 1557 to Ensure Language Access for Individuals with Limited English Proficiency?* (May 9, 2024), https://healthlaw.org/resource/what-is-required-under-title-vi-and-section-1557-to-ensure-language-access-for-individuals-with-limited-english-proficiency/.

¹⁹ 45 C.F.R. § 92.202(b).

²⁰ 45 C.F.R. § 92.4

²¹ 45 C.F.R. § 84.10

²² 504 Final Rule, Preamble, 89 Fed. Reg. at 40074.

²³ *Id.*

B. Discriminatory Benefit Design

The Section 1557 rule prohibits health insurance companies from discriminating through marketing practices and benefit designs.²⁴ Discriminatory benefit designs often result in denials of access to medically necessary care "particularly for individuals with disabilities who have significant health needs."²⁵ Examples of discriminatory benefit design might include cost-sharing structures, medical necessity definitions, narrow provider networks, drug formulary designs, network tiering, utilization management techniques, and other practices that are designed to deny or limit coverage to people with disabilities.²⁶ The Section 1557 rule notes that coverage denials or limitations "must not be based on unlawful animus or bias, or constitute a pretext for discrimination."²⁷ These provisions will help support health program beneficiaries, consumers, and advocates seeking to challenge discriminatory practices by insurers. No parallel provisions were incorporated into the Section 504 rules.

C. Community Integration

Both the Section 504 and Section 1557 rules stress the importance of community integration and ensuring that people with disabilities receive services in the least restrictive environment appropriate to their needs. As discussed above, Section 1557 prohibits health insurance companies from discriminating through marketing practices and benefit design.²⁸ These provisions also explicitly recognized that the law prohibits benefit designs that do not provide health insurance coverage in the least restrictive setting appropriate for an individual with a disability, and does not allow practices that may result in a serious risk of segregation or institutionalization for people with disabilities.²⁹

The 504 Rule includes several updates that clarify a covered entity's obligations to comply with the community integration mandate.³⁰ In the preamble, HHS notes that the updates align the

²⁴ 45 C.F.R. § 92.207.

²⁵ 1557 Final Rule, Preamble, 89 Fed Reg. at 37601.

²⁶ 1557 Final Rule, Preamble, 89 Fed. Reg. at 37601.

²⁷ 45 C.F. R. § 92.207(c).

²⁸ 45 C.F.R. § 92.207.

²⁹ 45 C.F.R. § 92.207(b)(6).

³⁰ 45 C.F.R. § 84.76

Section 504 rule with the ADA, *Olmstead*, and other case law.³¹ The rule specifies that all programs and services conducted by a covered entity must be provided in the most integrated setting that is appropriate for the needs of the person with a disability.³² The rule contains a non-exhaustive list of specific prohibited actions including:

- policies or practices that would restrict an individual's access to the most integrated setting;
- providing greater or more favorable benefits in a segregated setting;
- creating or applying more restrictive rules for individuals in integrated settings than for people in segregated settings; and
- failure to provide community-based services that would lead to the potential risk of institutionalization.³³

HHS also explains what constitutes a segregated setting, with a non-exhaustive list that includes: any congregate setting made up primarily of individuals with disabilities; programs that include a regimented set of daily activities; programs or facilities that have a lack of privacy or autonomy for participants; and any program with policies that restrict an individual's ability to receive visitors, engage in community activities, or manage their own activities of daily living.³⁴

D. Technology

Both rules contain protections against discrimination in covered programs' use of technology including telehealth, web, mobile apps, and kiosk platforms.³⁵ The provisions in the Section

³¹ 504 Final Rule, Preamble, 84 Fed. Reg. 40066; see also ACL 504 Blog (noting that the "rule clarifies obligations to provide services in the most integrated setting appropriate to the needs of individuals with disabilities, consistent with the Supreme Court's decision in *Olmstead v. L.C.*").

³² 45 C.F.R. § 84.76

³³ 45 C.F.R. § 84.76(c).

³⁴ 45 C.F.R. § 84.76(d)(1)-(d)(4).

³⁵ It should also be noted that in April of 2024, the U.S. Department of Justice issued a rule updating the title II regulations of the Americans with Disabilities Act. The new rule required includes specific requirements ensure that web and mobile content used by state and local governments is accessible to people with disabilities. See, U.S. Dep't of Justice, *Nondiscrimination on the Basis of Disability;* Accessibility of Web Information and Services of State and Local Government Entities, 28 C.F.R. Part 35, 89 Fed. Reg. 31320 (April 24, 2024), https://www.federalregister.gov/documents/2024/04/24/2024-07758/nondiscrimination-on-the-basis-of-disability-accessibility-of-web-information-and-services-of-state.

1557 rule related to technology are somewhat broad and general, noting that all covered entities must ensure that programs and services provided for individuals with disabilities through "information and communication technology" are accessible to people with disabilities.³⁶

The Section 504 rule contains more specific standards and technical requirements for web and mobile application accessibility. The rule requires covered entities to make web content and mobile applications readily accessible to people with disabilities. More specifically, the rule requires compliance with the Web Content Accessibility Guidelines (WCAG) 2.1 Level A and Level AA standards within two or three years of the publication of the rule, depending on the size of the covered entity.³⁷ HHS declined to provide specific measurability standards for kiosks and instead added a general nondiscrimination provision for programs and activities that use kiosks. More specifically, the rule noted that if a kiosk is not accessible, and a "workaround procedure" is created, such procedures must ensure that people with disabilities are afforded the same access, the same privacy, and the same convenience as nondisabled users that can access the kiosk.³⁸

E. Patient Care Decision Making Support Tools

The Section 1557 rule contains important protections against the use of discriminatory algorithms in health coverage and health care.³⁹ The rule specifically uses the term "patient care decision making tools" and notes that this term is defined broadly and encompasses wide variety of augmented or automated decision making tools that include things such as flowcharts, clinical guidelines, complex computer algorithms, and artificial intelligence (AI).⁴⁰ Many of these forms of automated decision making have been used widely in health care and evidence shows that they often result in bias, discrimination, and wrongful denials of necessary medical care.⁴¹ The updated final rule clearly prohibits the use of discriminatory patient care decision making tools in any covered health program of activity.⁴² The rule

³⁶ 45 C.F.R. § 92.204.

³⁷ 45 C.F.R. § 84.84.

³⁸ 45 C.F.R. § 84.83.

³⁹ 45 C.F.R. § 92.210.

⁴⁰ 45 C.F.R. § 92.210; Cassandra LaRose & Elizabeth Edwards, Nat'l Health Law Prog., *1557 Final Rule Protects Against Bias in Health Care Algorithms* (May 1, 2024), https://healthlaw.org/1557-final-rule-protects-against-bias-in-health-care-algorithms/.

⁴¹ *Id.*

⁴² 1557 Final Rule § 92.210.

includes an affirmative and ongoing duty for covered entities to identify patient decision making tools that utilize inputs measuring a protected class and to mitigate the risk that might happen as a use of those tools.⁴³

By contrast, the Section 504 rule does not contain any specific provisions addressing disability discrimination in automated decision-making tools or algorithms. The addresses the issue at length in the preamble, noting that the general prohibitions on disability discrimination in the rule encompass discrimination through the use of automated decision-making tools and algorithms, particularly in the context of medical treatment.⁴⁴ The final rule also asks for further feedback on this issue, noting that HHS is particularly interested in monitoring this type of discrimination in the context of medical treatment, child welfare programs, long term services and supports programs, and alternative payment models.⁴⁵

F. Medical Treatment Discrimination

The Section 504 rule specifically prohibits discrimination on the basis of disability in medical treatment. The final rule recognizes that there has been significant research and data showing that health care professionals disproportionately hold negative attitudes toward and inaccurate assumptions about people with disabilities.⁴⁶ This systemic undervaluation of the lives of people with disabilities has led to the disparate treatment of people with disabilities in medical care, created barriers to accessing medically necessary care, and often resulted in poorer health outcomes for people with disabilities.⁴⁷

HHS defines the term "medical treatment" in the final rule, noting in the preamble that it is a generic, nonspecific term that should be interpreted "in a broad and inclusive fashion to encompass a wide array of medical treatment services."⁴⁸ The final rule addresses three specific scenarios where discrimination in medical decision making might occur: a) denials of

⁴³ 45 C.F.R § 92.210(b)-(c).

⁴⁴ 504 Final Rule, Preamble, 89 Fed. Reg. at 40103.

⁴⁵ 504 Final Rule, Preamble, 89 Fed. Reg. at 40103

⁴⁶ Lisa I. lezzoni et al., *Physicians' Perceptions of People with Disability and Their Health Care*, 40 HEALTH AFFS. 297 (Feb. 2021),

https://pubmed.ncbi.nlm.nih.gov/33523739/; Nat'l Council on Disability, *Medical Futility and Disability Bias* 29 (Nov. 2019), https://ncd.gov/sites/default/files/NCD_Medical_Futility_Report_508.pdf.

⁴⁷ See e.g., Nat'l Council on Disability, Bioethics and Disability Report Series (2019), https://www.ncd.gov/report/bioethics-and-disability-report-series/.

⁴⁸ 504 Final Rule, Preamble, 89 Fed. Reg. at 40082-83.

medical treatment; b) denials of treatment for a separate symptom or condition; and c) the provision of medical treatment. Notably, this list of specific prohibitions is non-exhaustive. ⁴⁹ The general prohibition on medical treatment discrimination can and does reach beyond these three specific provisions.

The Section 504 rule prohibits denials of medical treatment where the denial is based on bias or stereotypes about an individual's disability; judgments that a person with a disability will be a burden on caregivers, family, or society; or beliefs that a life with a disability is not worth living, or is of lesser value than life without a disability.⁵⁰ This provision encompasses both explicit denials of treatment and the failure to offer treatment.⁵¹ A health care provider could not, for example, fail to offer sexual and reproductive health care to a person with disability if that refusal was based on a stereotype that, because of their disability, they are not or should not be sexually active.

The Section 504 rule also prohibits denials or limitations of clinically appropriate treatment for a separately diagnosable symptom or medical condition (whether or not that symptom or condition is connected to the individual's underlying disability), if that treatment would be offered to a similarly situated individual without a disability.⁵² For example, a provider could not deny a patient with HIV access to services that are unrelated to their HIV status, if that denial is due to biases about HIV status.

Finally, the Section 504 rule prohibits the provision of medical treatment to an individual with a disability when it would not be provided to an individual without a disability, "unless the disability impacts the effectiveness or ease of administration of the treatment itself or has a medical effect on the condition to which the treatment is directed."⁵³ This provision would prohibit, for example, requiring a person with a disability to accept long-acting contraception, sterilization, or abortion, when such a requirement would not be imposed on people without disabilities.⁵⁴

⁴⁹ Id. at 40092.

⁵⁰ 45 C.F.R. § 84.56(b)(1).

⁵¹ 504 Final Rule, Preamble, 89 Fed. Reg. at 40083.

⁵² 45 C.F.R. § 84.56(b)(2).

⁵³ 45 C.F.R. § 84.56(b)(3).

⁵⁴ 504 Final Rule, Preamble, 89 Fed. Reg. at 40095.

G. Value Assessment Methods

The Section 504 rule also addresses the use of discriminatory value assessment methods.⁵⁵ Value assessment methods are tools used by health care payers (both public and private) to calculate the perceived "value" of certain health care treatments, including prescription drugs. They are used to help guide decisions about whether or not to cover a treatment, and if so, the terms and conditions under which they are covered – such as eligibility, cost sharing, and other utilization management techniques.⁵⁶

Covered entities are prohibited from using "any measure, assessment, or tool that discounts the value of life extension on the basis of disability."⁵⁷ This means that any methodology used cannot treat the life of a person with a disability as having lesser value than the life of a person without a disability.⁵⁸ For example, Quality Adjusted Life Years (QALYs) are a measure used by payers, that theoretically evaluates the cost-effectiveness certain drug treatments, based on whether they extend or improve the quality of life of an individual.⁵⁹ However, measures like QALYs rely on a set of discriminatory assumptions that discount the value of life extension of people with disabilities based on subjective perceptions about quality of life.⁶⁰

H. Accessible Medical Diagnostic Equipment

The Section 504 rule also addresses the accessibility of medical diagnostic equipment (MDE) commonly found in health care settings. MDE includes equipment such as exam tables, weight scales, mammography equipment, radiology equipment, or other tools health care providers use for diagnostic purposes.⁶¹ In 2017, the U.S. Access Board published comprehensive standards for MDE.⁶² The final 504 rule adopts these standards and establishes an

⁵⁵ 45 C.F.R. § 84.57.

⁵⁶ 45 C.F.R. § 84.57; see also Nat'l Council on Disability, *Quality-Adjusted Life Years and the Devaluation of Life with a Disability* (Nov. 6, 2019), https://www.ncd.gov/report/quality-adjusted-life-years-and-the-devaluation-of-life-with-a-disability/ [hereinafter "NCD QALY Report"].

⁵⁷ 45 C.F.R. § 84.57

⁵⁸ *Id*.

⁵⁹ NCD QALY Report at 11.

⁶⁰ Carly Myers, Disability Rights Educ. and Def. Fund, *Pharmaceutical Analyses Based on the QALY Violate Disability Nondiscrimination Law* (Sept. 23, 2021), https://dredf.org/pharmaceutical-analyses-based-on-the-qaly-violate-disability-nondiscrimination-law/.

^{61 45} C.F.R. §§ 84.90-84.94.

⁶² 36 C.F.R. § 1195.1.

implementation timeline for covered entities to comply with the standards.⁶³ The Section 504 rule also specifies that, within two years, all covered entities must have at least one accessible weight scale, and one accessible exam table, provided they use such equipment.⁶⁴

Conclusion

Both the Section 1557 and 504 rules include important updates that help strengthen health coverage and improve access to care and services for people with disabilities. Both rules include updates that account for recent changes in law, technology, and service delivery, and include provisions that help ensure that people with disabilities receive care in the most integrated setting in their communities. Working together these rules encompass a wide variety of health care providers, health plans, and services, and help ensure that people with disabilities are protected from discrimination and bias.

⁶³ 45 C.F.R. § 84.90-.94.

⁶⁴ 45 C.F.R. § 84.92(b)-(c).