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HB 128: Prohibition of Discrimination Against Potential Organ Transplant Recipients

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HEALTH

General Provisions: Amend Chapter 1 of Title 31 of the Official Code of Georgia Annotated Relating to General Provisions Regarding Health, so as to Prohibit Providers from Discriminating Against Potential Organ Transplant Recipients Due Solely to the Physical or Mental Disability of the Potential Recipient to Provide for Definitions; Provide for Exceptions; Provide for Referrals and Recommendations; Provide for Compliance with Federal Requirements; Provide for Civil Action and Relief; Amend Chapter 24 of Title 33 of the Official Code of Georgia Annotated, Related to Insurance Generally, so as to Prohibit Health Insurers from Discriminating against Potential Organ Transplant Recipients Due Solely to the Physical or Mental Disability of the Potential Recipient; Provide for Definitions; Provide for Health Benefit Plans and Collective Bargaining; Provide for Applicability; Amend Chapter 39 of Title 31 of the Official Code of Georgia Annotated, Relating to Cardiopulmonary Resuscitation, so as to Revise Parental Requirement for Consent; Revise a Definition; Provide for a Short Title; Provide for Legislative Findings; Provide for Related Matters; Repeal Conflicting Laws; and for Other Purposes

CODE SECTIONS: O.C.G.A. §§ 31-1-24 (new); 31-39-2 (amended); 31-39-4 (amended); 33-24-59.30 (amended)

BILL NUMBER: HB 128

ACT NUMBER: 244

GEORGIA LAWS: 2021 Ga. Laws 546

SUMMARY: The Act functions to prohibit discrimination by health care providers and insurers against potential organ transplant recipients due to physical or mental disabilities. Also known as Gracie’s Law, the Act provides a pathway through local courts to enforce compliance, and an affected individual

may bring a civil action for injunctive and other equitable relief. In addition, the Act incorporates Simon’s Law, which provides that an order to not resuscitate a minor child can only be issued with the consent of the minor’s parents.

EFFECTIVE DATE: July 1, 2021

History

In 2019, Erin and David Nobles of Washington County, Georgia, discovered that their four-month-old child Gracie, born with Down syndrome and a heart defect, would require open-heart surgery.¹ But the Nobles family faced a second troubling quandary: should the surgery fail and Gracie require a transplant, could her disability impact her ability to receive a transplant?² People with disabilities in need of a transplant are often subject to “policies that exclude them as candidates or discrimination by physicians and centers that may brand them as lower priority.”³

Thankfully, Gracie’s surgery was successful, and her family did not personally have to find the answer to that question—but Gracie’s parents felt propelled by their new “awareness” of the discrimination that people with disabilities face to “push for greater protections for people living with an intellectual or developmental disability.”⁴ Although the Americans with Disabilities Act (ADA) provides protections against discrimination by granting access through federal

1. Jill Nolin, *Gracie’s Law Aims to Protect Organ Access for Georgians with Disabilities*, GA. RECORDER (Feb. 17, 2020, 8:12 AM), <https://georgiarecorder.com/2020/02/17/gracies-law-aims-to-protect-organ-access-for-georgians-with-disabilities/> [https://perma.cc/4GVM-RPR2]; Rahul Bali, *Governor Kemp Signs Gracie’s Law*, LAKE COUNTRY TODAY, <http://www.lakecountrytoday.com/2021/05/07/governor-kemp-signs-gracies-law/> [https://perma.cc/JT45-HMFN] (May 8, 2021).

2. Mariah Congedo, *Family Fighting to Pass ‘Gracie’s Law’ to Protect Georgians with Disabilities*, WTOC 11, <https://www.wtoc.com/2021/03/08/family-fighting-pass-gracies-law-protect-georgians-with-disabilities/> [https://perma.cc/DV56-T73G] (Mar. 7, 2021, 10:59 PM).

3. Nolin, *supra* note 1; Congedo, *supra* note 2.

4. Nolin, *supra* note 1.

courts, no similar level of protection is available through Georgia state courts.⁵

Erin and David approached State Representative Rick Williams (R-145th) to aid in their fight. Since then, they have worked closely together on a bill that creates “an immediate pathway through local courts” for affected individuals to pursue claims of discrimination by a provider or insurer.⁶ In conjunction with six cosponsors, Representative Williams originally introduced legislation, colloquially known as Gracie’s Law, in the 2019–2020 session of the Georgia General Assembly.⁷ After a unanimous vote in the House of Representatives and while waiting for a hearing before the Georgia Senate Health and Human Services Committee, the bill’s progress stalled when the COVID-19 pandemic brought the legislative session to a halt.⁸ Representative Williams reintroduced Gracie’s Law, however, as House Bill (HB) 128 in the 2020–2021 session.⁹

Bill Tracking of HB 128

Consideration and Passage by the House

Representative Rick Williams (R-145th) sponsored HB 128 in the House with Representatives Mack Jackson (D-128th), Danny Mathis (R-144th), Lauren McDonald (R-26th), Alan Powell (R-32nd), and Philip Singleton (R-71st) cosponsoring.¹⁰ The House read the bill for the first time on January 27, 2021, and for a second time the next day on January 28, 2021.¹¹ The bill was assigned to the House Health & Human Services Committee, and the Committee reported favorably on

5. *Id.*; Telephone Interview with Rep. Rick Williams (R-145th) (May 17, 2021) (on file with the Georgia State University Law Review) [hereinafter Williams Interview].

6. Nolin, *supra* note 1; Riley Bunch, *General Assembly Unanimously Backs ‘Gracie’s Law’*, VALDOSTA DAILY TIMES, https://www.valdostadailytimes.com/news/ga_fl_news/general-assembly-unanimously-backs-gracie-s-%20law/article_9e11fb84-90cf-11eb-b4e5-f76d1fd98c45.html [https://perma.cc/HBD4-M3PG] (Mar. 30, 2021).

7. Williams Interview, *supra* note 5; HB 842, as introduced, 2020 Ga. Gen. Assemb.; HB 842 (HCS), 2020 Ga. Gen. Assemb.

8. Williams Interview, *supra* note 5.

9. *Id.*; Georgia General Assembly, HB 128, Bill Tracking [hereinafter HB 128, Bill Tracking], <https://www.legis.ga.gov/legislation/58996>.

10. HB 128, Bill Tracking, *supra* note 9.

11. State of Georgia Final Composite Status Sheet, HB 128, May 13, 2021.

February 10, 2021.¹² On February 16, 2021, the House read HB 128 for a third time and subsequently passed it by a vote of 166 to 0.¹³

Consideration and Passage by the Senate

Senator Clint Dixon (R-45th) sponsored HB 128 in the Senate.¹⁴ The Senate first read the bill and referred it to the Senate Health and Human Services Committee on February 17, 2021.¹⁵ On March 25, 2021, the Committee reported favorably on the bill, and the Senate then read the bill for a second time.¹⁶

On March, 29, 2021, the Senate tabled, removed, and read the bill for a third time.¹⁷ That same day, Senator Dixon introduced a floor amendment along with Senators Russ Goodman (R-8th), Emanuel Jones (D-10th), Butch Miller (R-49th), and Chuck Payne (R-54th).¹⁸ The amendment added a second section to the bill and reorganized the section numbers accordingly.¹⁹ The amendment designated that only the first section would be referred to as Gracie's Law.²⁰ The second section added the requirement of parental consent for orders of non-resuscitation of a child.²¹ This amendment incorporated language from the former HB 212, referred to as Simon's Law, that never made it out of the Senate Committee of Health and Human Services.²² The Senate voted 52 to 0 to pass the bill as amended.²³

12. *Id.*

13. *Id.*; Georgia House of Representatives Voting Record, HB 128, #49 (Feb. 16, 2021).

14. HB 128, Bill Tracking, *supra* note 9.

15. State of Georgia Final Composite Status Sheet, HB 128, May 13, 2021.

16. *Id.*

17. *Id.*

18. *Id.*; HB 128 (SFA), 2021 Ga. Gen. Assemb.

19. HB 128 (SFA), 2021 Ga. Gen. Assemb.

20. *Id.* § 1-1, p. 1, l. 10.

21. *Id.* § 2-1 to -2, pp. 1-2, ll. 14-29.

22. State of Georgia Final Composite Status Sheet, HB 212, May 13, 2021; HB 212 (HCS), 2021 Ga. Gen. Assemb. The House passed HB 212 on February 18, 2021, by a vote of 170 to 0. Georgia House of Representatives Voting Record, HB 212, #61 (Feb. 18, 2021); Cole Muzio, *Hope Under the Gold Dome if We Can Keep It*, FAM. POL'Y ALL. (Feb. 11, 2021), <https://familypolicyalliance.com/issues/2021/02/11/hope-under-the-gold-dome-if-we-can-keep-it/> [<https://perma.cc/LY5G-7ASX>]. On February 22, 2021, HB 212 was read in the Senate and sent to the Committee on Health and Human Services. State of Georgia Final Composite Status Sheet, HB 212, May 13, 2021.

23. Georgia Senate Voting Record, HB 128, #335 (Mar. 29, 2021).

On March 31, 2021, the House voted 163 to 1 to pass the new version of HB 128.²⁴ The House sent the final bill to Governor Brian Kemp (R) on April 9, 2021, and he signed it into law as Act 224 on May 6, 2021.²⁵ The Act's effective date is July 1, 2021.²⁶

The Act

The Act amends the following portions of the Official Code of Georgia Annotated: Chapter 1 of Title 31, relating to general provisions regarding health; Chapter 24 of Title 33, relating to insurance generally; and Chapter 39 of Title 31, relating to cardiopulmonary resuscitation.²⁷ The Act's overall purpose is to "prohibit providers from discriminating against potential organ transplant recipients due solely to the physical or mental disability of the potential recipient."²⁸

Section 1-1

Section 1-1 titles Part I of the Act as Gracie's Law.²⁹

Section 1-2

Section 1-2 of the Act lists the General Assembly's findings in support of the Act. Subsection (1) acknowledges that a "mental or physical disability does not diminish a person's right to health care," and subsection (2) recognizes that, despite the protections that the ADA affords, many people with disabilities nevertheless "experience discrimination in accessing critical health care services."³⁰ Subsection (3) highlights some of the discriminatory reasons used to deny organ transplants for people with disabilities in other states, which, as subsection (4) indicates, are inappropriate selection criteria for

24. Georgia House of Representatives Voting Record, HB 128, #375 (Mar. 31, 2021).

25. State of Georgia Final Composite Status Sheet, HB 128, May 13, 2021.

26. 2021 Ga. Laws 546, § 1-2, at 546.

27. *Id.*

28. *Id.*

29. 2021 Ga. Laws 546, § 1-1, at 546.

30. 2021 Ga. Laws 546, § 1-2, at 546.

federally funded programs to use in evaluating transplant candidates.³¹ Subsection (5) concludes this section by stating that Georgia residents are “entitled to assurances that they will not encounter discrimination on the basis of a disability.”³²

Section 1-3

Section 1-3 of the Act amends Chapter 1 of Title 31 to add section 24.³³ Subsection (a) provides the definitions for all terms used in Code section 31-1-24.³⁴ Subsection (b) sets forth the primary substance of the Act and prohibits any covered entity from considering an individual ineligible for organ transplant solely on the basis of the individual’s disability.³⁵ The Act further proscribes five other practices related to organ transplant, such as refusing to refer a patient and placing a candidate lower on a waiting list solely on the basis of the candidate’s disability.³⁶ The Act carefully articulates, however, that physicians may still consider an individual’s disability when “medically significant” to the transplant.³⁷ At the same time, the Act requires that covered entities make “reasonable modifications to [their] policies, practices, or procedures” to ensure access to transplant and related services but only to the extent that such efforts would not “fundamentally alter” the nature of the covered entity’s services or result in an “undue burden.”³⁸

Subsection (c) provides a cause of action to the affected individual.³⁹ Should a violation occur, the affected individual may file a civil action in a local state district court to enforce compliance.⁴⁰ The court is then required to give the action “priority on its docket and expedited review.”⁴¹ The Act specifically notes that remedies are

31. *Id.* at 546–47.

32. *Id.* at 547.

33. 2021 Ga. Laws 546, § 1-3, at 547 (codified at O.C.G.A. § 31-1-24 (Supp. 2021)).

34. O.C.G.A. § 31-1-24(a) (Supp. 2021).

35. *Id.* § 31-1-24(b).

36. *Id.* § 31-1-24(b)(2)(A)-(E).

37. *Id.* § 31-1-24(b)(3).

38. *Id.* § 31-1-24(b)(5)-(6).

39. *Id.* § 31-1-24(c).

40. *Id.*

41. § 31-1-24(c)(2).

limited to equitable relief and that there is no right to compensatory or punitive damages.⁴²

Section 1-4

Section 1-4 amends Chapter 24 of Title 33 to add the new Code section 33-24-59.30, which relates to insurance generally.⁴³ Subsection (a) provides the definitions for all terms used in the new Code section.⁴⁴ Subsection (b) prohibits an insurance issuer who provides coverage for transplants from denying or reducing coverage to a covered person (a policyholder, subscriber, enrollee, member, or individual covered by a health benefit plan) solely because of that person's disability.⁴⁵ The Act further forbids insurance issuers from denying plan eligibility, enrollment, or renewal as a means of circumventing the Act's requirements.⁴⁶ Insurance issuers also cannot penalize, reduce or limit reimbursement to a provider, or give other incentives to persuade the provider to "provide care to a covered person in a manner inconsistent with this Code section."⁴⁷

Section 2-1

Section 2-1 amends Code section 31-39-2, which relates to cardiopulmonary resuscitation.⁴⁸ Specifically, the Act modifies paragraph (10), which defines "parent," by adding the phrase "person with legal authority to act on behalf of a minor."

Section 2-2

Section 2-2 amends Code section 31-39-4, which relates to persons authorized to issue orders not to resuscitate.⁴⁹ The Act modifies

42. *Id.* § 31-1-24(c)(2), (4).

43. 2021 Ga. Laws 546, § 1-4, at 550-51 (codified at O.C.G.A. § 33-24-59.30 (Supp. 2021)).

44. O.C.G.A. § 33-24-59.30(a) (Supp. 2021).

45. *Id.* § 33-24-59.30(b).

46. *Id.* § 33-24-59.30(b)(2).

47. *Id.* § 33-24-59.30(b)(3).

48. 2021 Ga. Laws 546, § 2-1, at 551 (codified at O.C.G.A. § 31-39-2 (2019 & Supp. 2021)).

49. 2021 Ga. Laws 546, § 2-2, at 551(codified at O.C.G.A. § 31-39-4 (2019 & Supp. 2021)).

subsection (d) to include more restrictive language regarding when to issue an order not to resuscitate.⁵⁰ In its previous version, a parent could consent “orally or in writing to an order not to resuscitate his or her minor child.”⁵¹ Now, the Act adds the word “only” and provides that “an order not to resuscitate may be issued *only* with the oral or written consent of the minor’s parent unless an exception applies”⁵²

Analysis

Georgia’s HB 128 is not the first bill of its kind.⁵³ Despite the ADA’s general ban on disability-based discrimination, physicians and organ transplant centers continue to discriminate in the organ transplant selection process.⁵⁴ Given the insufficient protections of federal law, some state legislatures have introduced and adopted nondiscrimination bills.⁵⁵ Accordingly, Georgia’s passage of HB 128 is a step toward a more ethical allocation of medical resources.⁵⁶

Insufficiency of the Americans with Disabilities Act’s Coverage

Discrimination can occur in multiple stages of the organ transplant process.⁵⁷ First, physicians discriminate by failing to refer patients

50. *Id.*

51. O.C.G.A. § 31-39-4(d) (2019).

52. 2021 Ga. Laws 546, § 2-2, at 546 (codified at O.C.G.A. § 31-39-4(d) (Supp. 2021)) (emphasis added).

53. Jennifer Bosk, *The Fight for Gracie’s Law*, GA. COUNCIL ON DEVELOPMENTAL DISABILITIES, <https://gcd.org/blogs/making-a-difference-blog/3405-the-fight-for-gracie-s-law.html> [<https://perma.cc/9BC6-GM3N>].

54. NAT’L COUNCIL ON DISABILITY, ORGAN TRANSPLANT DISCRIMINATION AGAINST PEOPLE WITH DISABILITIES 11, 30–31 (2019) [hereinafter NCD REPORT], https://ncd.gov/sites/default/files/NCD_Organ_Transplant_508.pdf [<https://perma.cc/XGK5-QVQ4>]; *Nondiscrimination in Organ Transplantation Laws & Toolkit*, NAT’L DOWN SYNDROME SOC’Y [hereinafter *Nondiscrimination Toolkit*], <https://www.ndss.org/programs/ndss-legislative-agenda/healthcare-research/nondiscrimination-in-organ-transplantation-laws-toolkit/> [<https://perma.cc/QPN9-C5KU>].

One of the ADA’s central purposes is “to provide clear, strong, consistent, enforceable standards addressing discrimination against individuals with disabilities.” 42 U.S.C. § 12101(b)(2).

55. NCD REPORT, *supra* note 54, at 13; *Nondiscrimination Toolkit*, *supra* note 54.

56. NCD REPORT, *supra* note 54, at 21.

57. *See id.* at 25, 28.

with disabilities to organ transplant centers for consideration.⁵⁸ Notably, “[a] 2004 survey, the most recent one available, found that only 52 percent of people with disabilities who requested a referral to a specialist regarding an organ transplant evaluation actually received a referral,” a lower rate of referral than patients without disabilities.⁵⁹ Next, organ transplant centers discriminate by refusing to evaluate the candidacy of a person with a disability for transplant, by evaluating the person with a disability unfairly, or by failing to place a person with a disability on a transplant list.⁶⁰

Titles II and III of the ADA prohibit “public entit[ies]” or places of “public accommodation” from discriminating against someone with a disability by reason of their disability.⁶¹ The language of these sections ban discrimination by both public and private hospitals and organ transplant centers.⁶²

In practice, however, the lack of either litigation enforcing the ADA or clear federal guidance in this area has produced continuing discrimination by physicians and organ transplant centers.⁶³ Additionally, “the informal manner in which organ transplant eligibility decisions are often made makes it difficult to determine whether discrimination occurred.”⁶⁴ Some medical providers contend that people with disabilities experience poorer transplant outcomes, but “studies consistently find that transplant outcomes for people with disabilities are no worse than transplant outcomes for people without disabilities.”⁶⁵

58. *Id.* at 29.

59. *Id.*

60. *Id.* at 29–32.

61. 42 U.S.C. §§ 12132, 12182; NCD REPORT, *supra* note 54, at 49.

62. NCD REPORT, *supra* note 54, at 49.

63. *Id.* at 49–50.

64. *Id.* at 50. For example:

A 2009 study of pediatric transplant centers stated that 69 percent of those surveyed reported that their transplant center’s process for evaluating the relevance of neurodevelopmental disability to eligibility for an organ transplant, on a scale of 1 to 5, was mostly “informal, implicit, or unstated” as opposed to “formal, explicit, and uniform.”

Id. at 32.

65. *Id.* at 38–39, 54.

Other State Law Efforts

To address the discrimination that federal law fails to prevent, many state legislatures have passed laws in the past ten years that specifically ban organ transplant discrimination.⁶⁶ States introduced these bills either in response to an individual case of discrimination or after the efforts of advocacy organizations.⁶⁷ Like HB 128, each of these laws prohibits discrimination but allows consideration of a disability where the disability is medically significant to the transplant's ability to succeed.⁶⁸

In 1996, California became the first state to enact similar legislation.⁶⁹ But New Jersey started the current wave of legislative action in 2013.⁷⁰ From 2013 to 2020, Maryland, Massachusetts, Oregon, Delaware, Kansas, Ohio, Pennsylvania, Washington, Louisiana, Indiana, Virginia, Iowa, Missouri, and Florida passed similar statutes.⁷¹ Along with Georgia, the following states adopted nondiscrimination statutes during their 2021 legislative sessions: Arkansas, Oklahoma, Wyoming, Nevada, Minnesota, Tennessee, Texas, Montana, and Colorado.⁷²

Maryland's 2015 statute, which the legislature based on a model written by the Autistic Self Advocacy Network, took coverage a step further than former statutes.⁷³ The statute not only prohibits the denial of placement on a transplant waiting list based on disability but also prohibits placing a person with a disability in a lower priority position on a transplant waiting list.⁷⁴ The language of Georgia's bill emulates the Maryland and the Autistic Self Advocacy Network's model.⁷⁵

66. *Id.* at 57.

67. *Id.* at 58.

68. NCD REPORT, *supra* note 54, at 58.

69. *Id.* at 57; *Nondiscrimination Toolkit*, *supra* note 54.

70. NCD REPORT, *supra* note 54, at 57–58; *Nondiscrimination Toolkit*, *supra* note 54.

71. NCD REPORT, *supra* note 54, at 58–59; *Nondiscrimination Toolkit*, *supra* note 54.

72. *Nondiscrimination Toolkit*, *supra* note 54.

73. *Id.*; NCD REPORT, *supra* note 54, at 60.

74. NCD REPORT, *supra* note 54, at 60; *Nondiscrimination Toolkit*, *supra* note 54.

75. Compare 2021 Ga. Laws 546, §1-3, at 548, with MD. CODE ANN., HEALTH–GEN. §§ 20-1601 to -1606 (West, Westlaw through 2021 Regular Session of the General Assembly).

Lastly, Massachusetts's legislation imposes a deterrent fine of up to \$50,000 in civil actions.⁷⁶

Conclusion

The recent enactment of each state's legislation, including Georgia's HB 128, makes its efficacy unknown.⁷⁷ Above all, HB 128 gives victims of discrimination access to a cause of action in the Georgia judicial system. But at the same time, Georgia must continue to monitor to see whether the legislation effectively affords victims of discrimination relief in its state courts. For instance, litigants may encounter difficulty proving discrimination in the informal transplant evaluation process.⁷⁸ So, an additional legislative step may be needed to make transplant centers formalize their processes for evaluating placement on transplant waiting lists. At the very least, the new legislation brings awareness to the issue of organ transplant discrimination and discourages continued failure to comply with the ADA. Ultimately, the unanimous passage of HB 128 shows that Georgia is committed to preventing discrimination in organ transplants and to giving parents' greater control over their child's do-not-resuscitate decision.

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76. NCD REPORT, *supra* note 54, at 58.

77. NCD REPORT, *supra* note 54, at 68.

78. *See supra* text accompanying note 64.