

GENERAL ASSEMBLY OF NORTH CAROLINA  
SESSION 2021

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HOUSE BILL 642  
PROPOSED COMMITTEE SUBSTITUTE H642-PCS30413-BP-13

Short Title: Down Syndrome Organ Trans. Nondiscrim. Act.

(Public)

Sponsors:

Referred to:

April 26, 2021

1 A BILL TO BE ENTITLED  
2 AN ACT PROHIBITING ORGAN TRANSPLANT DISCRIMINATION ON THE BASIS OF  
3 DISABILITY BY HEALTH CARE PROVIDERS, DONOR MATCHING ENTITIES, AND  
4 HEALTH INSURERS.

5 The General Assembly of North Carolina enacts:

6 SECTION 1. This act shall be known and may be cited as the "Down Syndrome  
7 Organ Transplant Nondiscrimination Act."

8 SECTION 2.(a) Article 16 of Chapter 130A of the General Statutes is amended by  
9 adding a new Part to read:

10 "Part 4A. Nondiscrimination in Organ Transplantation.

11 "**§ 130A-414.1. Legislative findings and declaration of policy.**

12 The General Assembly of North Carolina makes the following findings and declaration:

- 13 (1) A mental or physical disability does not diminish a person's right to health  
14 care.
- 15 (2) The Americans with Disabilities Act of 1990, 42 U.S.C. § 12101 et seq., as  
16 amended, prohibits discrimination against individuals with disabilities, yet  
17 many individuals with disabilities still experience discrimination in accessing  
18 critical health care services.
- 19 (3) In other states nationwide, individuals with mental and physical disabilities  
20 have been denied lifesaving organ transplants based on assumptions that their  
21 lives are less worthy, that they are incapable of complying with post-transplant  
22 medical requirements, or that they lack adequate support systems to ensure  
23 compliance with post-transplant medical requirements.
- 24 (4) Although organ transplant centers must consider medical and psychosocial  
25 criteria when determining if a patient is suitable to receive an organ transplant,  
26 transplant centers that participate in Medicare, Medicaid, and other federally  
27 funded programs are required to use patient selection criteria that result in a  
28 fair and nondiscriminatory distribution of organs.
- 29 (5) North Carolina residents in need of organ transplants are entitled to assurances  
30 that they will not encounter discrimination on the basis of a disability.

31 The General Assembly hereby declares that the life of an individual with a disability who  
32 needs an organ transplant is as worthy and valuable as the life of an individual without a disability  
33 who needs the same medical service.

34 "**§ 130A-414.2. Definitions.**

35 The following definitions apply in this Part:



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- 1           (1) Anatomical gift. – A donation of all or part of a human body to take effect  
2           after the donor's death for the purpose of transplantation or transfusion.
- 3           (2) Auxiliary aids or services. – An aid or service that is used to provide  
4           information to an individual with a cognitive, developmental, intellectual,  
5           neurological, or physical disability and is available in a format or manner that  
6           allows the individual to better understand the information. An auxiliary aid or  
7           service may include any of the following:
- 8           a. Qualified interpreters or other effective methods of making aurally  
9           delivered materials available to persons with hearing impairments.
- 10          b. Qualified readers, taped texts, texts in accessible electronic format, or  
11          other effective methods of making visually delivered materials  
12          available to persons with visual impairments.
- 13          c. Supported decision-making services, including any of the following:
- 14           1. The use of a support individual to communicate information to  
15           the individual with a disability, ascertain the wishes of the  
16           individual, or assist the individual in making decisions.
- 17           2. The disclosure of information to a legal guardian, authorized  
18           representative, or another individual designated by the  
19           individual with a disability for such purpose, as long as the  
20           disclosure is consistent with State and federal law, including  
21           sections 261 through 264 of the Health Insurance Portability  
22           and Accountability Act of 1996, P.L. 104-191, as amended,  
23           and any federal regulations adopted to implement these  
24           sections.
- 25           3. If an individual has a court-appointed guardian or other  
26           individual responsible for making medical decisions on behalf  
27           of the individual, any measures used to ensure that the  
28           individual is included in decisions involving the individual's  
29           health care and that medical decisions are in accordance with  
30           the individual's own expressed interests.
- 31           4. Any other aid or service that is used to provide information in  
32           a format that is easily understandable and accessible to  
33           individuals with cognitive, neurological, developmental, or  
34           intellectual disabilities, including assistive communication  
35           technology.
- 36          (3) Covered entity. – Any licensed provider of health care services, including  
37          licensed health care practitioners, hospitals, nursing facilities, laboratories,  
38          intermediate care facilities, psychiatric residential treatment facilities,  
39          institutions for individuals with intellectual or developmental disabilities, and  
40          prison health centers.
- 41          (4) Disability. – As defined in the Americans with Disabilities Act of 1990, 42  
42          U.S.C. § 12102 et seq., as amended.
- 43          (5) Organ transplant. – The transplantation or transfusion of a part of a human  
44          body into the body of another for the purpose of treating or curing a medical  
45          condition.
- 46          (6) Qualified recipient. – Any individual who has a disability and meets the  
47          essential eligibility requirements for the receipt of an anatomical gift with or  
48          without any of the following:
- 49           a. Individuals or entities available to support and assist the individual  
50           with an anatomical gift or transplantation.
- 51           b. Auxiliary aids or services.

1           c.     Reasonable modifications to the policies, practices, or procedures of a  
2                 covered entity, including modifications to allow for either or both of  
3                 the following:

4                 1.     Communication with one or more individuals or entities  
5                     available to support or assist with the recipient's care and  
6                     medication after surgery or transplantation.

7                 2.     Consideration of support networks available to the individual,  
8                     including family, friends, and home and community-based  
9                     services, including home and community-based services  
10                    funded through Medicaid, Medicare, another health plan in  
11                    which the individual is enrolled, or any program or source of  
12                    funding available to the individual, when determining whether  
13                    the individual is able to comply with post-transplant medical  
14                    requirements.

15     **"§ 130A-414.3. Organ transplant discrimination on the basis of disability prohibited.**

16     (a) It is unlawful for a covered entity to do any of the following, solely on the basis of an  
17     individual's disability:

18             (1)     Consider an individual ineligible to receive an anatomical gift or organ  
19                     transplant.

20             (2)     Deny medical services or other services related to organ transplantation,  
21                     including diagnostic services, evaluation, surgery, counseling, and  
22                     post-operative treatment and services.

23             (3)     Refuse to refer the individual to a transplant center or other related specialist  
24                     for the purpose of being evaluated for or receiving an organ transplant.

25             (4)     Refuse to place a qualified recipient on an organ transplant waiting list.

26             (5)     Place a qualified recipient on an organ transplant waiting list at a lower  
27                     priority position than the position at which the individual would have been  
28                     placed if the individual did not have a disability.

29             (6)     Refuse insurance coverage for any procedure associated with being evaluated  
30                     for or receiving an anatomical gift or organ transplant, including  
31                     post-transplantation and post-transfusion care.

32     (b) Notwithstanding the provisions of subsection (a) of this section, a covered entity may  
33     take an individual's disability into account when making treatment or coverage recommendations  
34     or decisions, solely to the extent that the disability has been found by a physician or surgeon,  
35     following an individualized evaluation of the individual, to be medically significant to the  
36     provision of the anatomical gift.

37     (c) If an individual has the necessary support system to assist the individual in complying  
38     with post-transplant medical requirements, a covered entity may not consider the individual's  
39     inability to independently comply with post-transplant medical requirements to be medically  
40     significant for the purposes of subsection (b) of this section.

41     (d) A covered entity shall make reasonable modifications to its policies, practices, or  
42     procedures to allow individuals with disabilities access to transplantation-related services,  
43     including diagnostic services, surgery, coverage, post-operative treatment, and counseling,  
44     unless the covered entity can demonstrate that making such modifications would fundamentally  
45     alter the nature of such services.

46     (e) A covered entity shall take steps necessary to ensure that an individual with a  
47     disability is not denied medical services or other services related to organ transplantation,  
48     including diagnostic services, surgery, post-operative treatment, or counseling, due to the  
49     absence of auxiliary aids or services, unless the covered entity demonstrates that taking these  
50     steps would fundamentally alter the nature of the medical services or other services related to  
51     organ transplantation or would result in an undue burden for the covered entity.

1 (f) The provisions of this section apply to all stages of the organ transplant process.

2 (g) Nothing in this Part shall be construed to require a covered entity to make a referral  
3 or recommendation for or perform a medically inappropriate organ transplant.

4 "§§ 130A-414.4 through 130A-414.9. Reserved for future codification purposes.

5 "§ 130A-414.10. Enforcement.

6 (a) Whenever it appears that a covered entity has violated or is violating any of the  
7 provisions of this Part, the affected individual may commence a civil action for injunctive and  
8 other equitable relief against the covered entity for purposes of enforcing compliance with this  
9 Part. The action may be brought in the district court for the county where the affected individual  
10 resides or resided or was denied the organ transplant or referral.

11 (b) In an action brought under this Part, the court shall give priority on its docket and  
12 expedited review, and may grant injunctive or other equitable relief, including any of the  
13 following:

14 (1) Requiring auxiliary aids or services to be made available for a qualified  
15 recipient.

16 (2) Requiring the modification of a policy, practice, or procedure of a covered  
17 entity.

18 (3) Requiring facilities be made readily accessible to and usable by a qualified  
19 recipient.

20 The Court may not award compensatory or punitive damages for violations of this Part.

21 (c) Nothing in this Part is intended to limit or replace available remedies under the  
22 Americans with Disabilities Act, 42 U.S.C. § 12102 et seq., as amended, or any other applicable  
23 federal or State laws."

24 **SECTION 2.(b)** This section applies to anatomical gifts that become available for  
25 transplantation on or after October 1, 2021.

26 **SECTION 3.(a)** Article 3 of Chapter 58 of the General Statutes is amended by adding  
27 a new section to read:

28 **"§ 58-3-256. Coverage related to organ transplants.**

29 (a) For the purposes of this section, the following definitions apply:

30 (1) Anatomical gift. – The donation of all or part of a human body to take effect  
31 after the donor's death for the purpose of a transplant.

32 (2) Disability. – As defined in the Americans with Disabilities Act of 1990, 42  
33 U.S.C. § 12102 et seq., as amended.

34 (3) Health benefit plan. – As defined in G.S. 58-3-167.

35 (4) Insurer. – As defined in G.S. 58-3-167.

36 (5) Transplant. – The transplantation or transfusion of a part of a human body into  
37 the body of another human for the purpose of treating or curing a medical  
38 condition.

39 (b) No insurer offering a health benefit plan in this State that provides coverage for  
40 anatomical gifts, organ transplants, or treatment and services related to anatomical gifts or  
41 transplants shall do any of the following:

42 (1) Deny coverage to an insured solely on the basis of that individual's disability.

43 (2) Deny to an individual eligibility, or continued eligibility, to enroll or to renew  
44 coverage under the terms of a health benefit plan solely for the purpose of  
45 avoiding the requirements of this section.

46 (3) Attempt to induce a health care provider to provide care to an insured in a  
47 manner inconsistent with this section by doing either of the following:

48 a. Penalizing, or otherwise reducing or limiting the reimbursement of, a  
49 health care provider.

50 b. Providing monetary or nonmonetary incentives to a health care  
51 provider.

- 1           (4)   Reduce or limit health benefit plan coverage benefits to an insured for any
- 2                   services related to organ transplantation performed determined to be necessary
- 3                   in consultation with the attending physician and the insured.
- 4       (c)   Reserved for future codification purposes.
- 5       (d)   In the case of a health benefit plan maintained pursuant to one or more collective
- 6 bargaining agreements between employee representatives and one or more employers, any
- 7 amendment to the health benefit plan made pursuant to a collective bargaining agreement solely
- 8 to conform to this section shall not be treated as a termination of the collective bargaining
- 9 agreement.
- 10       (e)   Nothing in this section shall be deemed to require an insurer to provide coverage for
- 11 a medically inappropriate organ transplant."
- 12       **SECTION 3.(b)** G.S. 58-3-102(b) is recodified as G.S. 58-3-256(c).
- 13       **SECTION 3.(c)** G.S. 58-3-102, as amended by this section, is repealed.
- 14       **SECTION 3.(d)** This section applies to insurance contracts entered into, renewed,
- 15 or amended on or after October 1, 2021.
- 16       **SECTION 4.** This act becomes effective October 1, 2021.