

AMERICAN MEDICAL ASSOCIATION HOUSE OF DELEGATES

Resolution: 022
(A-22)

Introduced by: Pennsylvania

Subject: Organ Transplant Equity for Persons with Disabilities

Referred to: Reference Committee on Amendments to Constitution and Bylaws

1 Whereas, People with Intellectual and developmental disabilities (IDD) still face discrimination in
2 access of care, specifically regarding barriers of access to transplant surgery^{1,2}, despite federal
3 and local guidelines which protect against discrimination on the basis of disability³; and
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5 Whereas, Transplant centers and medical professionals are unaware or noncompliant with
6 clauses of the Americans with Disabilities Act, Rehabilitation Act, and Affordable Care Act
7 prohibiting discrimination against people with disabilities⁴ as is applied to the organ transplant
8 process²; and
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10 Whereas, A 2004 survey found that only 52 percent of people with disabilities who requested a
11 referral to a specialist regarding an organ transplant evaluation actually received a referral,
12 while 35 percent of those “for whom a transplant had been suggested” never even received an
13 evaluation⁵; and
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15 Whereas, A 2008 survey of pediatric transplant centers found that 43 percent always or usually
16 consider intellectual disabilities an absolute or relative contraindication to transplant due to
17 assumptions and that in some cases, organ transplant centers may categorically refuse to
18 evaluate a patient with a disability as a candidate for transplant⁶; and
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20 Whereas, Throughout their medical education, Health, Oral Health, and Vision Health providers
21 receive limited training on the special needs of people with IDD related to common problems
22 and delivery of services⁷, and patients report feeling that physicians generally have little
23 understanding of living with a disability⁵; and
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25 Whereas, If a person has a disability that is unrelated to the reason a person needs an organ
26 transplant, the disability will generally have little or no impact on the likelihood of the transplant
27 being successful⁸ and making assumptions regarding post-transplant quality of life for people
28 with IDD violates AMA ethics⁹; and
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30 Whereas, Congress established the need for an organization, the Organ Procurement and
31 Transplant Network (OPTN), to facilitate the organ transplantation system across the many
32 transplant centers and sources of organ donors in an efficient manner. The effective guidelines
33 for organ allocation do not include disability status in non-discrimination section 5.4.A¹¹; and
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35 Whereas, Titles II and III of the Americans with Disabilities Act (ADA) prohibit discrimination
36 against people with disabilities in all programs, activities and services of public entities and
37 prohibit private places of public accommodation from discriminating against people with
38 disabilities³; and

1 Whereas, Section 504 of the Rehabilitation Act of 1973 prohibits federally funded programs
2 including hospitals from denying qualified individuals the opportunity to participate in or benefit
3 from federally funded programs, services, or other benefits, denying access to programs,
4 services, benefits or opportunities to participate as a result of physical barriers, and denying
5 employment opportunities they are otherwise entitled or qualified⁴; and
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7 Whereas, Section 1557 of the Affordable Care Act prohibits discrimination on the basis of race,
8 color, national origin, sex, age, or disability in certain health programs or activities and ensures
9 physical access for individuals with disabilities to healthcare facilities and appropriate
10 communication technology to assist persons who are visually or hearing impaired¹²; therefore
11 be it
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13 RESOLVED, That our American Medical Association support equitable inclusion of people with
14 Intellectual and Developmental Disabilities (IDD) in eligibility for transplant surgery (New HOD
15 Policy); and be it further
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17 RESOLVED, That our AMA support individuals with IDD having equal access to organ
18 transplant services and protection from discrimination in rendering these services (New HOD
19 Policy); and be it further
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21 RESOLVED, That our AMA support the goal of the Organ Procurement and Transplantation
22 Network (OPTN) in adding disability status to their Nondiscrimination policy under the National
23 Organ Transplant Act of 1984 (New HOD Policy); and be it further
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25 RESOLVED, That our AMA work with relevant stakeholders to distribute antidiscrimination
26 education materials for healthcare providers related to equitable inclusion of people with IDD in
27 eligibility for transplant surgery. (Directive to Take Action)

Fiscal Note: Not yet determined

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References:

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10. Organ Procurement and Transplantation Network Policies. (2020). https://optn.transplant.hrsa.gov/media/1200/optn_policies.pdf
11. Section 1557 of the Patient Protection and Affordable Care Act. Relevant RFS & AMA Policy: Medical Care of Persons with Developmental Disabilities H-90.968 6.2.2 Directed Donation of Organs for Transplantation Tissue and Organ Donation H-370.983