



A Partnership of The Arc & United Cerebral Palsy

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U.S. Department of the Treasury
Internal Revenue Service

U.S. Department of Labor
Employee Benefits Security Administration

U.S. Department of Health and Human Services
Centers for Medicare & Medicaid Services

RE: Interim Final Rules Prohibiting Discrimination Based on Genetic Information in Health Insurance Coverage and Group Health Plans

Thank you for giving the Disability Policy Collaboration (DPC) the opportunity to submit comments to the Interim Final Rules Prohibiting Discrimination Based on Genetic Information in Health Insurance Coverage and Group Health Plans published in the Federal Register on October 7, 2009, Vol. 74, No. 193.

DPC is a joint venture of The Arc of the United States (The Arc) and United Cerebral Palsy (UCP) that focuses on legislative and legal supports to improve the lives of individuals with disabilities and their families. The Arc is a membership organization of 732 state and local chapters made up of people with intellectual, developmental and other disabilities, their families, friends, interested citizens, and professionals in the disability field. UCP is an organization that provides services and advocacy to people with disabilities through a nationwide network of over 100 organizations. Both The Arc and UCP have represented individuals with disabilities for nearly 60 years.

DPC commends the Departments for their consultation and coordination with the scientific community, with other relevant Federal agencies, and with the public in the development of these rules. They provide strong, unequivocal prohibitions against the improper use or disclosure of genetic information.

DPC offers the following comments to specific portions of the rules.

§54.9802-1(c)(2)(i); §2590.702(c)(2)(i); §146.121(c)(2)(i) Prohibiting discrimination against participants and beneficiaries based on a health factor.

DPC supports the addition of a cross reference which clarifies that covered entities may not increase group premiums or contribution rates based on genetic information of one or more individuals in the group. The addition will ensure that there can be no misunderstanding or misinterpretation of the rules. The example provided in (c)(2)(iii) helps illustrate the meaning of the prohibition.

§54.9802-3T(a); §2590.702-1(a); §146.122(a) Additional requirements prohibiting discrimination based on genetic information. Definitions.

(1) Collect

DPC supports the addition of the definition of “collect” that includes requesting, requiring, or purchasing information.

(2) Family member

The rules broadly define “family member” in keeping with Congressional intent that the term be broadly construed. DPC supports the clarifying language added to the statutory definition of family member concerning relatives by affinity and by less than full consanguinity. DPC also supports the inclusion of non-exhaustive lists of persons who are first-, second-, third-, or fourth-degree relatives. The lists add clarity to the definition of family member.

(4) Genetic services

The definition of “genetic services” in the rules mirrors statutory language. DPC believes that additional, clarifying language would be helpful. The suggested new language is included in the Supplementary Information section of the proposed HIPPA Administrative Simplification: Standards for Privacy of Individually Identifiable Health Information rule (45 CFR Parts 160 and 164; Federal Register Vol. 74, No. 193, October 7, 2009). DPC suggests the language in the Supplementary Information be included as new language in the definition of genetic services as follows: (suggested new language is underscored)

Genetic services means:

- (i) A genetic test, as defined in paragraph (a)(5) of this section, including the fact that an individual or a family member of the individual requested or received a genetic test;
- (ii) Genetic counseling (including obtaining, interpreting, or assessing genetic information), including the fact that an individual or a family member of the individual requested or received genetic counseling;
- (iii) Genetic education, including the fact that an individual or a family member of the individual requested or received genetic education.

(5) Genetic test

DPC supports the addition of examples in the rules that help clarify what is and what is not a genetic test.

(6) Manifestation or manifested

DPC supports the addition of a definition of “manifestation or manifested” and of numerous examples in the rules that illustrate the meanings of manifestation and manifested.

(7) Underwriting purposes

The language in the rules is very clear that premiums or contribution amounts may not be adjusted for a group on the basis of genetic information. DPC suggests that language which is included in Supplementary Information: II. Overview of the Regulations, Prohibition on Adjusting Group Rates be added to this section as follows (suggested new language is underscored):

§54.9802-3T(a)(7)(b)(1); §2590.702-1(a)(7)(b)(1); §146.122(a)(7)(b)(1) *In general.* For purposes of this section, a group health plan, and a health insurance issuer offering health insurance coverage in connection with a group health plan, must not adjust premium or contribution amounts for the plan, or any group of similarly situated individuals under the plan, on the basis of genetic information. Even when a plan or issuer has lawfully obtained genetic test results or other genetic information (for example, an acquisition that took place prior to GINA’s effective date), the plan or issuer is still prohibited from using that information to adjust premiums or contribution amounts.

§54.9802-3T(d)(1)(ii)(A)(B); §2590.702-1(d)(1)(ii)(A)(B); §146.122(d)(1)(ii)(A)(B)

DPC strongly supports the addition of language to the definition of underwriting purposes concerning health risk assessments (HRAs) and wellness programs. The language significantly strengthens the protections against the inappropriate use of genetic information and disclosure of genetic information. Employers will still be able to offer wellness programs, but will not be able to request genetic information through wellness programs to modify benefits, offer discounts, or adjust premiums. Covered entities will be prohibited from using financial incentives or disincentives to coerce participation in a wellness program or HRA that collects genetic information. Health plans will not be able to discriminate against employees with respect to compensation, terms, conditions, or privileges because of genetic information.

§54.9802-3T(d)(2)(ii); §2590.702-1(d)(2)(ii); §146.122(d)(2)(ii) DPC has concerns about the incidental collection exception to the prohibition on collection of genetic information. The rule states that if it is reasonable to anticipate that health information will be received as part of the collection of information, the incidental collection exception applies if the entity seeking the information explicitly states that genetic information should not be collected. DPC believes that an explicit statement that genetic information *must* be removed should accompany every request for medical information. DPC also believes that health care providers who are recipients of requests for medical information should be required to make every effort to remove genetic information. Given that such removal may be very difficult in some circumstances, DPC recommends that the Departments explore cost-effective means of ensuring that medical records are screened and that genetic information is removed before health information is shared.

DPC believes that covered entities should notify consumers when genetic information is collected inadvertently. The notice should explain that genetic information, which was obtained incidentally, will not be used for purposes of underwriting.

§54.9802-3T(d)(3) and (e); §2590.702-1(d)(3) and (e); §146.122(d)(3) and (e) The numerous examples included in the rules to illustrate prohibitions on collection of genetic information are very helpful, as are the examples that illustrate determining medical appropriateness.

Respectfully submitted,

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