

Meeting of February 25, 2009 - on Notice of Proposed Rulemaking Implementation of Title II of the Genetic Information Non-Discrimination Act of 2008

Statement of Andrew J. Imparato President and CEO American Association of People with Disabilities

Acting Chairman Ishimaru, Acting Vice-Chair Griffin, and Commissioners:

Thank you for this opportunity to speak on the occasion of the release of EEOC's Notice of Proposed Rulemaking (NPRM) implementing Title II of the Genetic Information Non-Discrimination Act. I look forward to reading the proposed rule you are issuing today and plan to submit formal comments on the rule once I have had an opportunity to review it and consult with our coalition partners.

My name is Andrew Imparato and I am the President and CEO of the American Association of People with Disabilities (AAPD). Founded on the fifth anniversary of the Americans with Disabilities Act (ADA), AAPD organizes the disability community to be a powerful force for change—politically, socially and economically. With more than 100,000 members, AAPD is the largest cross-disability membership organization in the U.S. In the public policy arena, AAPD advocates for policies that advance the goals of the ADA—equality of opportunity, full participation, independent living, and economic self-sufficiency.

Prior to joining AAPD in 1999, I served as general counsel and director of policy for the National Council on Disability, as an attorney adviser with EEOC Commissioner Paul Steven Miller, as counsel to the U.S. Senate Subcommittee on Disability Policy, and as a staff attorney at the Disability Law Center in Boston. In 2002, while the genetic non-discrimination legislation was making its way through Congress, I testified before the Senate Health, Education, Labor and Pensions Committee in support of the legislation, noting the difficulties with relying exclusively on the ADA to address discrimination on the basis of genetic information.

I am delighted that the last Congress passed both the Genetic Information Non-Discrimination Act and the ADA Amendments Act. Read together, these two critical statutes will help to plug a big hole in civil rights protections that was created by Supreme Court and lower federal court decisions interpreting the ADA. I called attention to that hole when I testified in support of GINA in 2002 and last year when I testified before the House Education and Labor Committee in support of the ADA Restoration Act (the original name of the Amendments Act).

As a person with bipolar disorder, a condition that I understand to have a genetic link, I am delighted that GINA will provide protections to my two boys and future generations who may have a genetic predisposition to develop some version of my condition and a host of other conditions. GINA will protect my sons as long as they have not developed symptoms of the condition. Should they develop symptoms, the new provisions in the ADA Amendments Act will now provide protections against employment discrimination based on those symptoms.

As EEOC works simultaneously to issue regulations implementing Title II of GINA and the new ADA Amendments Act, I encourage you to seize this opportunity to not just develop and issue regulations, but to undertake a broad-based effort to educate the disability community and the various disease-specific groups who are directly affected by these laws.

When I worked at the National Council on Disability, we did a series of reports looking at the effectiveness of federal enforcement of a variety of civil rights laws. The major lesson from these reports was that educating the protected class about their rights and how to assert those rights in the face of discrimination is the most effective strategy for ensuring widespread implementation and enforcement of civil rights protections for people with disabilities. I strongly encourage EEOC to look at the broad-based training that was conducted in the early 1990s after passage of the ADA, and fund a new round of training that includes both the ADA Amendments Act and GINA. The other major new law that could be part of such a training, if it were done in partnership with the Department of Labor, is the mental health parity legislation.

As I said, I look forward to reviewing your proposed GINA regulations. With the proliferation of new genetic technologies, I recognize that we are all likely to have access to more and more genetic information about ourselves and our families over time. I think as a society we are still grappling with how to use this information and the potential benefits and risks of undergoing genetic testing.

As I see it, EEOC's job is to do everything in your power to minimize the potential risks that genetic testing could have a negative impact on a person's current employment or future jobs. This can be accomplished by restricting the ability of employers to obtain genetic information, protecting the confidentiality of the information after it is acquired by an employer, and prohibiting discrimination on the basis of the information. In the rulemaking process, I encourage EEOC to interpret the statutory language, including the exceptions to the general rule against the acquisition of genetic information by employers, in a manner that provides the greatest protection for employees and is easy for employees and employers to understand.

EEOC is also uniquely well-suited to look at the interaction between the GINA rules and other workplace non-discrimination laws like the ADA and the Rehabilitation Act. I encourage EEOC to read these laws in a way that provides seamless protection for people with genetic anomalies who are both symptomatic and asymptomatic. The same rule should apply in the workplace for both populations—treat people fairly and evaluate them based on their performance and not based on speculation about how that performance might be affected by a gene-linked condition.

Thank you again for the opportunity to address the Commission at this time of important progress in workplace protections for people with disabilities, chronic health conditions, and genetic predispositions. I look forward to working with you to implement these new laws in a manner that improves employment outcomes for people with disabilities and provides real safeguards for people who are evaluating whether to undergo genetic testing.