

Should genetic counselors dissuade termination of pregnancies with Down syndrome risk?

Several people have sent me a perspective piece by bioethicist Art Caplan in [PLOS Biology](#), "*Chloe's Law: A Powerful Legislative Movement Challenging a Core Ethical Norm of Genetic Testing*." The concise and compelling article considers legislation to mandate that genetic counselors talk to their patients more about positive aspects of having a child with trisomy 21 Down syndrome.

Studies show that as availability of prenatal screening (for risk) and testing (for diagnosis) for the condition have increased, births of affected children have decreased. That is, most pregnant women who learn that the fetus has trisomy 21 Down syndrome end the pregnancy. Yet genetic counseling is, historically, largely value-neutral or "non-directive." Offer the medical facts, explain how tests work and what results mean, listen, and try to intuit the patient's views to guide word choices. ("Termination" vs "abortion," for example). Answer questions, but don't try to sway clinical decision-making.

I concur with Dr. Caplan that mandating genetic counselors to more positively spin life with trisomy 21 Down syndrome may obscure the medical and scientific facts, misleading patients.

Throughout the 1980s and 1990s, I often met with women who were of "advanced maternal age" (35+) explaining the benefits and risks of having the invasive procedures amniocentesis or chorionic villus sampling (CVS) to check fetal chromosomes. But since the Internet arrived, I do very little counseling of this type because patients can learn much of what I'd tell them on their own. Today patients can know more about genetics than their physicians.

The GLP aggregated and excerpted this blog/article to reflect the diversity of news, opinion and analysis. Read full, original post: Disappearing Down Syndrome, Genetic Counseling, and Textbook Coverage