

Providing Basic Genetic Services: What Role for Family Planning Clinics?

By Rachel Benson Gold

By all accounts, the field of reproductive genetics has exploded in recent years. Public attention has focused largely on a dazzling set of technologies to diagnose conditions in pregnant women and fetuses; according to a 2004 report from the Genetics and Public Policy Center, the number of diagnosable conditions increased nearly 10-fold to over 1,000 between 1993 and 2003. Meanwhile, a set of simpler, less expensive interventions also has emerged that can help women and couples make informed decisions about whether to become pregnant and increase the chances of a healthy birth when they do.

The nationwide network of nearly 7,700 family planning clinics serves almost seven million women of reproductive age each year. For many of these women, a clinic visit is likely their primary, if not only, interface with the health care system—giving family planning providers a unique ability to reach women prior to pregnancy. Moreover, clients in family planning clinics already look to the clinic for a package of care well beyond contraceptive services. One in seven women of reproductive age who have a Pap test each year or who are tested or treated for a gynecologic infection does so at a family planning clinic. Clinics serve one in three women who are tested or treated for a sexually transmitted infection.

By offering a range of “low-tech” genetic services—from the provision of basic information and education to individualized counseling and referrals for genetic blood tests and to the

testing itself—family planning clinics could make a significant contribution both to the “genetics revolution” and to the broader field of preconception care. In so doing, they could forge closer and longer lasting ties with their clients and expand their community presence. Clearly, however, taking on this service set offers challenges as well as opportunities.

Informing Pregnancy Decisions

At least in theory, the package of care provided at family planning clinics could be expanded to offer women information and education that could be important to them in evaluating their risk for adverse birth outcomes. The basic health assessment routinely completed at a client’s initial visit, for example, could be used to identify women with conditions that might place them at high risk, such as a family history of hemophilia or another genetic abnormality. Such women could be given information about the condition and, on request, referred for testing to determine whether they may be, in fact, carriers who could pass it on to their offspring.

Even when there is no known family history, the basic health assessment could be used to elicit useful genetic information, such as inclusion in a specific population group with an elevated risk. For example, thalassemia is especially prevalent among people of African, Southeast Asian or Mediterranean descent. The gene for sickle cell anemia is prevalent among people from west and central Africa, the Mediterranean, the Middle East and parts of India.

Tay-Sachs occurs primarily among Jews of northern European descent as well as Canadians from eastern Quebec and Franco-Americans in New England. Again, women could be educated about their potential risk, and those considering pregnancy might choose to be referred for specific testing.

In short, the basic health assessment routinely provided in family planning clinics—assuming sufficient support—could be leveraged to help women and couples make informed decisions about whether and under what conditions to become pregnant. Meanwhile, other services could be offered to improve the likelihood of a healthy birth outcome when clients do choose pregnancy.

Preventing Neural Tube Defects...

Chief among these are interventions arising from the now-established fact that folic acid supplementation reduces the likelihood a woman will bear a child afflicted with a neural tube defect, such as spina bifida or anencephaly. These conditions, which can be fatal or lead to lifelong disability, are among the most common birth defects in the United States.

Because supplementation must begin prior to pregnancy to be effective, the U.S. Public Health Service since 1992 has recommended that all women of childbearing age capable of becoming pregnant take a folic acid supplement daily. Last year, the federal Centers for Disease Control and Prevention (CDC) reported that the incidence of neural tube defects fell by one-quarter from 1996 to 2001, but more recent data are troubling. According to a 2005 Gallup survey conducted for the March of Dimes, the proportion of women of childbearing age who reported taking folic acid supplements fell from 40% in 2004 to 33% in 2005. While the proportion of women knowing that folic acid prevents birth defects stayed constant, the proportion

knowing that folic acid should be taken before pregnancy decreased from 12% to 7%.

Clearly, family planning clinics are well-positioned to contribute to the ongoing national campaign against neural tube defects, educating clients on the importance of folic acid supplementation and, with adequate subsidy, providing the vitamins themselves. Notably, because folic acid supplementation is needed by all women of reproductive age, it requires no screening by the clinic to identify high-risk women.

...And Other Disabilities

In contrast, clients with a specific risk factor could be identified through clinics' routine health assessment and engaged in a discussion of steps to increase the likelihood of a healthy pregnancy outcome. Some risks are now widely known—for example, that a child born to a woman who contracts rubella during pregnancy can suffer a range of debilitating conditions including blindness and mental retardation. The March of Dimes recommends that women be tested for immunity prior to pregnancy and consider vaccination if they are not immune. (Vaccinations cannot be given during pregnancy.) Clinics could offer at-risk women information on the implications of rubella infection during pregnancy and refer them for immunity testing and/or vaccination as appropriate.

Other risks are more obscure, but no less important to identify. For example, asking whether a woman was on a special diet during childhood could indicate whether she had phenylketonuria (PKU). Since the 1960s, infants diagnosed with PKU have been put on a special diet in order to prevent mental retardation. Once the child's brain is fully formed, the diet is usually discontinued. But when a woman who had PKU reaches childbearing age, the

lingering chemical imbalance in her blood could cause disabilities in her offspring. Preliminary information strongly suggests that an intervention as simple as reinstating the special diet at least three months prior to pregnancy may reduce the likelihood that the imbalance reoccurs.

Two States' Efforts

Some family planning programs are already venturing down the road of providing some genetics information and services, often in collaboration with other public health programs or nonprofit agencies such as the March of Dimes.

The Illinois health department, for example, has been at the forefront of attempting to integrate preconception care into its family planning efforts. All state-funded family planning agencies provide basic preconception education to clients, including information on the importance of folic acid supplementation, but beginning in 1994, the state has encouraged agencies to establish identifiable preconception counseling programs. These efforts, operational in 16 of the state's 54 family planning agencies, combine general education with counseling and referral of clients identified as having a specific need or risk. Agencies with an approved protocol are eligible for an enhanced counseling reimbursement rate from the state.

Meanwhile, in collaboration with the health department, the Illinois March of Dimes has sponsored a folic acid vitamin distribution project in the family planning programs run by four local health departments and two Planned Parenthood affiliates. This effort has provided vitamin supplies to nearly 7,000 women over the past two years. In early 2004, with the pilot project winding down, the state moved to ensure a more stable funding source—requesting that the federal Centers for Medicare and Medicaid Services (CMS) include dis-

tribution of folic acid vitamins as a reimbursable service under the state's Medicaid family planning expansion. The request, which is pending at CMS, received important support when the March of Dimes described it as "an extraordinary opportunity to prevent birth defects."

A similar effort was recently pilot-tested by the Oklahoma Department of Health in three family planning clinics across the state. Over the course of an 18-month test, 100 clients in each site filled out a short self-appraisal tool designed to gauge risk. Clients who had a personal or family history of a particular genetic condition, or who belonged to a group at risk, were referred for additional counseling. All participants were educated about the importance of folic acid supplements and given a three-month supply of vitamins. At the end of the three-month period, clients returned for a follow-up visit and were provided an additional one-year supply of the supplements. The effort is currently being pilot-tested in physicians' offices.

Emerging Opportunities

These efforts dovetail with an emerging consensus about the overall importance of preconception care. In 2002, the American College of Obstetricians and Gynecologists and the American Academy of Pediatrics recommended that the health care provided to women during their reproductive years "should include counseling on appropriate medical care and behavior to optimize pregnancy outcomes." This summer, the CDC held a National Summit on Preconception Care to bring the medical community, researchers, advocates, government agencies and others to the table to develop recommendations for preconception care.

Clearly, family planning providers have a unique potential that could be tapped in this regard. Yet, maxi-

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mizing that potential—or even taking modest steps in that direction—presents significant challenges. Initiating even a relatively simple program to provide basic information to clinic clients generally about folic acid supplementation to prevent neural tube defects involves building institutional expertise, developing protocols and procedures, training staff and monitoring the effort.

Agencies wanting to go further to counsel and perhaps even become a testing site for individual clients with a specific risk also would need to seek out and build relationships with other providers in the community to whom they could refer women in need of additional, more specialized services. And those agencies desiring to establish identifiable preconception genetic programs would need to craft ways to identify the subset of their clientele who

might be most interested and to develop effective messages with which to reach them.

Clearly, some women going to family planning clinics to obtain contraceptive services will not be receptive to programs geared at preparing for pregnancy. But some are likely to be. Half of all clients seen at clinics funded through the Title X family planning program are in their 20s and nearly one in four are in their 30s; many of these women may well be thinking about having children in the not-so-distant future and may be interested in a preconception health assessment that includes information about genetics issues.

All of these efforts are costly, however. At a time when public funding for family planning programs is stagnating and the cost of providing basic contraceptive and related diagnostic services is rising, even those providers most committed to initiating preconception efforts would need

to look to new sources of support, whether from public programs, the private sector or both.

Yet, offering basic preconception genetic services offers important potential benefits for family planning providers. Such efforts could help them build continuing relationships with their existing clients that go beyond their need for contraception. By positioning themselves as a source of information and health care for women thinking about or trying to become pregnant, clinics could market themselves more broadly as community resources for family planning and preconception services at different points in women's lives. And these efforts could strengthen clinics' ties to their local maternal and child health communities. Still, whether the challenges outweigh the opportunities will be something that individual providers will need to weigh in light of their own resources and community needs. ☉



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120 Wall Street, 21st floor
New York, NY 10005

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