

Diversity in Genetic Counseling: Past, Present and Future

Ilana Suez Mittman · Katy Downs

Received: 29 March 2007 / Accepted: 20 March 2008
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Abstract Despite decades of efforts to increase ethnic and racial diversity among genetic counselors, African Americans, Hispanics and American Indians, currently constituting almost one-third of Americans, remain only meagerly represented among genetic counselors at a level far under that seen in other health professions. This paper provides the first comprehensive effort to archive published and unpublished initiatives to increase ethnic and racial diversity in the profession. It also provides a review of national data and diversity initiatives in the health workforce in general. The paper reviews diversity initiatives in other health professions and suggests ways to improve recruitment and retention of underrepresented populations into genetic counseling. Increasing the diversity of the genetic counseling workforce stands not only to expand access to genetic services but also to improve the quality of genetic care provided to the American public.

Keywords Genetic counseling · Diversity · Health disparities · Recruitment · Retention · Minority · Under represented minorities (URM)

Introduction

This paper examines professional issues pertaining to diversity in the genetic counseling profession. Included are a review of professional policies, activities, and strategic plans pertaining to diversity and an examination of similar issues in other health professions. While in genetic counseling (as in most health occupations) diversity is mostly regarded in terms of ethnicity, race and gender, it is important to recognize that *everybody* contributes to diversity because each one of us is different from the majority in at least one way. The assumption that diversity pertains only to socially visible groups of people is as false as assuming that racial and cultural issues are inherent domains of certain groups only.

In this paper, we focus on ethnic and racial diversity, especially pertaining to African Americans, Hispanics and Native Americans, because these groups' limited representation in genetic counseling is persistent, has not changed over decades of interventions, and is very significant in comparison to some professions. However, we recognize the significance of inclusion and diversity in a broadened scope, and hope that this paper will contribute to building a conceptual framework for this very important matter.

The Case for Health Workforce Diversity

Ethnic and racial minorities suffer significant and persistent health disparities regarding preventable and treatable conditions in comparison to other populations (IOM 2002). As illustrated by a landmark report released by the Institute of Medicine in March 2002, health disparities persist even when controlling for insurance status, disease severity and site of care;

I. S. Mittman
Department of Epidemiology and Preventive Medicine,
University of Maryland,
Baltimore, MD, USA

K. Downs
Department of Otolaryngology-Head & Neck Surgery,
University of Michigan,
Ann Arbor, MI, USA

K. Downs
Wayne State University School of Medicine,
Detroit, MI, USA

I. S. Mittman (✉)
Maryland Department of Health and Mental Hygiene,
Office of Minority Health and Health Disparities,
807 S Clinton Street,
Baltimore, MD 21224, USA
e-mail: ilana.mittman@gmail.com

Genetics (ASHG) revealed that African Americans and Hispanics comprised 1.47% and 3.15% of the membership, respectively (personal communications, 3/5/07).

Specific ethnic and racial demographics for members of the American Board of Medical Genetics (both PhD and MD level) are available from a 3-year national research project designed to assess genetic services (Cooksey et al. 2005; Cooksey et al. 2006). The study established that the vast majority of both MD and PhD clinical geneticists were white; African Americans comprised only 1% of both MD and PhD geneticists, and Hispanics made up only 2% of both groups.

The International Society of Genetic Nurses (ISONG) does not currently collect ethnic and racial data from its members. However, a 2004 cross-sectional descriptive survey of US genetic nurses revealed that only 6% were ethnic and racial minorities (Lea et al. 2006).

Membership in Other Allied Health Professions

In comparison to other mental health and health care professionals, genetic counselors are among the least likely to be African American, Native American or Hispanic. As shown in Table 1, information from the Bureau of Labor Force Statistics suggests that the genetic counseling profession is among health professions with the *lowest* participation of African Americans and Hispanic Americans compared to a host of medical and allied health professions (Kosanovich 2006).

Barriers to Participation of Ethnic and Racial Minorities in Health Professions

Entering and graduating from a health professional school happens at the “downstream” end of an educational pipeline that starts with an individual’s earliest school experience. For minorities, this pipeline is “leaky” at multiple points.

Overt public policies prohibiting or limiting access to educational opportunities based on race are part of our national history. Slavery, segregation, substandard educational opportunities in economically depressed areas and the recent challenges to race conscious admissions have placed minorities at a distinct educational disadvantage (Barnes 2007; Cordes and Miller 2005; Educational Broadcasting Corporation 2004). On average, when compared with White students, racial and ethnic minorities receive a K-12 education of measurably lower quality, score lower on standardized tests, and are less likely to complete high school. Moreover, those who graduate from college are far less likely to graduate from a 4-year college than their White counterparts (Cohen 2005).

A multitude of barriers to academic success among minorities is cited in the literature. These include social vulnerability as minority students often recount feelings of isolation, and lack of support in predominantly white institutions (Gardner 2005a, b; Gilchrist and Rector 2007; Maton and Hrabowski 2004). There are also issues of lack of academic preparation leading to poor study habits and inadequate test taking skills (Gilchrist and Rector 2007). Lack of adequate minority faculty presents another key barrier to a successful academic experience for minorities as it limits the availability of guidance and mentorship for individuals who may be the first in their families to attain higher education (Moreno et al. 2006). Financial barriers significantly limit access to higher education among minorities. The cost of application, tuition and ancillary fees as well as the financial impact of deferring a steady income may be detrimental in accessing higher education especially for individuals who lack family support, and/or are supporting others. Finally, lack of exposure of ethnic and racially diverse youth to the scope of health careers is a major deterrent to their entering such professions (Gonzalez et al. 2000; Marcelin et al. 2004; Stewart et al. 2002; Thomson et al. 1991).

Table 1 National Data on Health Workforce Diversity, by Gender, Race and Ethnicity

Profession	Men (%)	African American (%)	Hispanic/Latino (%)	Asian American (%)	Total minorities (%)
Social workers	22.3	20.4	10.9	2.9	34.2
Clinical laboratory technicians	28	14.6	6.9	10.2	31.7
Physician assistants	32.7	6.8	9.4	7.6	23.8
Registered nurses	7.8	10.1	4.4	6.8	21.3
Physical therapists	34.6	7.1	3.3	10.3	20.7
Occupational therapists	7.3	5.1	3.7	8.8	17.6
Medical geneticists	50.0	1.0	2.0	8.0	11.0
Psychologists	33.3	3.3	4.6	1.4	9.3
Speech language pathologist	4.9	6.0	2.1	0.5	8.6
Genetic counselors	9.0	1.0	1.0	5.0	7.0

Source: Bureau of Labor Force Statistics (2006), NSGC Professional Status Survey, 2004

Table 2 Highlights of Past Efforts to Increase Diversity in the Genetic Counseling Profession

Year	Effort	Initiated and/or supported by
1979	NSGC By laws designate six regions to ensure geographic representation on Board of Directors	By Laws Committee
	Criteria for full membership expanded to include professionals in addition to those with masters in genetic counseling	By Laws Committee
1980/1981	First Professional Issues Survey collects demographic data on membership including sex and geographic area	Professional Issues Committee NSGC
1991	"Encouragement of diversity in the field of genetic counseling" sighted as vision for the profession	Ad hoc Long Range Planning Committee, International Congress of Human Genetics
1992	Ethnocultural Issues in Genetic Counseling Recruitment and Education conference for Program Directors	Education Committee NSGC
1993	Diversity Among Genetic Counselors Subcommittee formed to encourage "more heterogeneity within our profession, targeting groups currently underrepresented: racial, ethnic and culture minorities, men and those with disabilities. In existence ~2 years	Genetic Services Committee, NSGC
	"Ethnocultural diversity and genetic counseling training: The challenge for a twenty-first century" published	D Pinales-Morejon and R Rapp, Journal of Genetic Counseling (JGC)
	"Minority recruitment into the genetic counseling profession" published	SC Smith, NS Warren and L Misra JGC
	Mailing targeted to undergraduates attending Historically Black Colleges and Universities (HBCU's) with cover letter encouraging applications from qualified individuals of all ethnocultural groups	Jon Weil Membership Committee NSGC
1994–1997	Genetic Services Branch of the Maternal and Child Health Bureau awarded 3 year grant "Genetic-LINC; Liaisons Into Cultures"	Ilana Mittman Baltimore Sinai Hospital and Howard University
1996	Meeting agenda included: Recruitment: increase and retain the membership of the NSGC, with special attention to minorities and students	Membership Committee NSGC
	Dissemination of NSGC college recruitment poster targeted to quality minority undergraduate institutions and to specific areas of the country	Membership Committee NSGC
	Set objective to identify minority-focused college career guidebooks and internet sites in which to list genetic counseling as a career	Membership Committee NSGC
1997	Slide presentation to encourage minority applications	Stacey Wong and Arlyn Tanega, graduate students at Northridge
1997	Diversity SIG formed	NSGC members
1998	Strategic Plan included "encourage diversity"	NSGC
1999	Diversity Task Force (DTF) appointed	Wendy Uhlmann, President NSGC
2000	DTF survey sent to all NSGC members	
	DTF final report submitted to NSGC Board of Directors (BOD)	
2003	Diversity SIG reformed into Diversity Subcommittee of Membership Committee	Kathryn Spitzer Kim Membership Committee NSGC
2004	2004–2006 Strategic Plan included a goal to "Increase visibility of genetic counseling as a profession with emphasis on diversity" with the tactic to "Identify and implement effective recruitment methods" and the related outcomes to '1. Achieve plan for minority recruitment 3/05; Implement plan by 6/05; 2. Achieve increase in minority representation by 9/06"	NSGC
2005	Genetic counselor and students featured on "sistagirls.org" website	Katy Downs Diversity Sub-Committee
2005–2006	Career brochures developed for minority recruitment	N Steinberg Warren Membership Committee
2006	Community outreach to primarily African American undergraduate students held during the 2006 AEC in a community location	Tené Hamilton Franklin Diversity Subcommittee NSGC

were no more than 30 practicing minority genetic counselors at that time (verbal communications). Since the total NSGC membership was 593 in 1985, minority representation in the profession was 5%.

In 1991, a sub-committee of the NSGC education committee received funding from the Office of Human

Genome Research in the National Institute of Health, for Ethical, Legal and Social Implications (ELSI) project. This funding supported a 3-day conference in 1992, in Asilomar, California, to bring together program directors of all genetic counseling training programs to explore ethnocultural issues in genetic counseling and recruitment and retention

Table 3 Diversity Efforts in Genetic Counseling Training Programs in North America—Workshop on Diversity Recruitment, October 1997

Activity	Number	Percentage
Presentations to minority undergraduate institutions on genetic counseling	11	52.3
Presentations to high schools with minority students	7	33
Mail information to schools with a high enrollment of minority students	5	23.8
Outreach education to biology teachers in high schools	3	14.2
Present at career fairs	3	14.2
Have minority graduate students take part in recruitment	2	9.5
Establish a special fund for minority students	1	4.7
Establish a minority graduate advisory committee on recruitment	1	4.7
No activities reported	9	42.8

N=21 programs

ethnicity by expanding areas of diversity to include: country of origin, language(s) spoken, religious affiliation, disability, sexual orientation, presence of a genetic condition, and socioeconomic status as they pertain to perceived discrimination, recruitment strategies, and professional status. In addition, the survey elicited perceptions of respondents' academic and professional careers as well as perceptions of discrimination pertaining to training, job seeking and career advancement. The survey was mailed to 1,705 genetic counselors, and returned by 904 (53% response rate), with 898 surveys containing usable data.

Among other findings, demographic data revealed that 14% of respondents were foreign-born and 18.9% were bilingual. Under-represented counselors were more likely to report less satisfaction with their career trajectory, and to perceive discrimination in employment, career advancement and the training experience. Due to the age of the data (now 9 years) we wish to caution readers about the findings' relevance. However, we recommend that additional studies of genetic counselors' perceptions related to diversity be conducted. We are willing to share our survey and additional findings with interested parties.

Learning From the Experiences of Others: Diversity Status in Other Health Professions

Achieving inclusiveness regarding diversity is espoused by most academic and professional institutions but is indeed a challenging prospect. Minority participation in health professions does not follow a uniform trend. While

increases in membership diversification that approach URM representation in the population at large have been shown in professions such as baccalaureate nursing, public health and pharmacy (Grumbach et al. 2003), other professions show little or no improvement. In 2004, only 6.4% of practicing US physicians were URMs (Association of American Medical Colleges 2006a). Similarly, in that year 9% of the nation's nurses (at all levels of training) and 5% of dentists were either Hispanics, African Americans or Native Americans (Sullivan 2004). Importantly, as has been shown in a government report on mental and behavioral health professions (Duffy et al. 2004) the vast majority of traditional mental health professionals such as social workers, counselors, marriage and family therapists and pastoral counselors were non-Hispanic white.

Best and Promising Practices in Increasing Minority Participation in Health Careers

Given limited resources for increasing workforce diversity, it is paramount to build upon the work of others. The Institute of Medicine (IOM) report on health disparities led to a growing awareness of career paths barriers to biomedical professions experienced by racial/ethnic minorities (Agrawal et al. 2005; Association of American Medical Colleges 2006a; Brady 2004; Institute of Medicine 2001, 2004). A review of the medical literature for minority recruitment efforts in the health workforce predominantly yielded publications pertaining to schools of medicine and nursing. Publications on minority recruitment into various counseling professions are surprisingly sparse. For that reason we will mostly draw on experiences in diversifying medical and nursing education and experiences pertaining to enrolling minorities into science major tracks at the undergraduate level. In general, successful strategies for increasing diversity in the various health professions include *pipeline preparation* of inner city students for Science, Engineering, Technology and Math (STEM); dispelling myths about science and medical careers; making available early faculty and peer mentoring; offering pre-college summer programs, as well as post-baccalaureate preparation for graduate education; financial assistance such as scholarship and Loan Forgiveness programs, and, creating a hospitable climate for minority students in predominantly white institutions (Cohen and Steinecke 2006; Grumbach and Chen 2006; Maton and Hrabowski 2004; Table 4).

Diversity in Medical Education

The AAMC has been diligent and tenacious in its efforts to diversify medical education. Project "3,000 by 2,000" presents the most comprehensive effort to increase diversity

nursing profession is the high rate of attrition of minority students from training programs in nursing estimated to range from 15% to 85% (Gardner 2005a, b).

Facing critical issues of workforce shortage, lack of desired diversity, problems in retention of minority nursing students, and shortage of mentors in general and minority mentors in particular, nursing programs around the country have taken various action strategies. Several nursing schools have established mentoring programs that match first and second year students with advanced nursing students. Schools have also revised their nursing curricula to include cultural competency training, increased focus on holistic approaches to patient care, and service learning opportunities for their students through partnering with diverse communities. Nursing schools are also increasing the accessibility of their classes to individuals who have both work and home obligations by providing distant learning opportunities, after hour classes, and off campus classroom locations. Some schools have set aside special funds for minority students and many nursing scholarships organizations also offer financial awards (All Nursing Schools 2007).

Science, Technology, Engineering and Math (STEM)

There are several programs in the nation that boost college level interest and preparation in biomedical careers such as the Meyerhoff Scholars Program at the University of Maryland Baltimore County, and the Biology Scholars Program at the University of California Berkeley (Maton and Hrabowski 2004; Matsui et al. 2003). These programs employ strategies that include on-going rich mentorship, study group participation, and extended opportunities for research. Their success is demonstrated by recent data showing that ethnic and racial minorities are not only as interested as their peers in pursuing college-level science studies, but they also increasingly are choosing biology and sciences majors in college, and demonstrating a greater likelihood of enrolling in graduate studies in these subjects (Raymond and Lue 2006).

Discussion

Despite over two decades of efforts to increase diversity among genetic counselors, the profession's gender and ethnic and racial demographics remain relatively unchanged. Findings from the study of Lega et al. (2005) indicate that we can expect little change in the next few years. Moreover, data reported by the American Society of Human Genetics, International Society of Genetic Nurses, and the American Board of Medical Genetics, all confirm similar levels of extremely low participation of under-represented minorities in genetic careers.

As illustrated earlier, the problem is not unique to the genetic counseling profession since higher-paying, better-known professions similarly are struggling to recruit and retain minorities. However, a level of 2–3% representation of African Americans, Hispanic Americans and Native Americans among genetic professionals, when these groups' constitution in the US population is ten times as high, is rather disquieting.

While this paper describes an impressive number of diversity initiatives within the profession, it is our opinion that they are disjointed, sporadic, and variously lack realistic goals and effective implementation and evaluation strategies. For example, the Strategic Plan of 2004–2006 created a timeline that was doomed to failure. It called for implementation of a minority recruitment plan 3 months after it was developed and then a demonstration of increased diversity in just 1 year from implementation. Considering the labor intensive process of increasing awareness among potential applicants, the application and enrollment process, and then 2 years of graduate training, such a timeline is not realistic. Indeed it needs to be recognized that there are no “quick” fixes for a situation that has been long in the making; rather, perseverance and patience will prove rewarding.

The few attempts made to explore reasons for the low percentage of ethnic and racial minorities in the field tend to focus on recruitment and training. When exploring the under-representation of ethnic/racial minorities in the genetic counseling profession it is imperative to look not only at recruitment per se, but also at retention, training experience, professional “climate” in general, and specifics related to mentoring, job satisfaction and career advancement. Such issues are key to retention and career satisfaction.

Oh and Lewis (2005) proposed the Genetic Counseling Career Pathway Model (GCCPM), which focuses on promoting awareness of the genetic counseling profession leading to application to graduate programs and progression from training into graduation and employment. However, their model fails to include career track progression and job satisfaction which are important factors in assuring not only retention of minority genetic counselors but also the availability of minority role models and mentors.

Schoonveld et al. (2007) illustrated that racial minority counselors are presumed to be “spokes persons” on diversity issues and are expected to demonstrate advocacy in these areas. Their findings raise an important issue regarding career opportunities for under-represented minorities. Will these individuals be able to freely pursue their areas of interest, or will they feel obligated to participate in activities not of their choosing, thereby detracting from other areas of career building?

Training costs and perceived earning potential seem to be obstacles to recruitment of racial minorities into genetic

Educational Recommendations

Recruitment Strategies

An aggressive campaign to showcase genetic careers is needed as it has been shown that intense outreach education regarding the genetic counseling profession is lacking (Oh and Lewis 2005; Schoonveld et al. 2007; Smith et al. 1993). The creation of an interactive web environment promoting a career in genetic counseling could prove beneficial and help disseminate information about the profession through extensive links to secondary and post-secondary educational institutions. An example could be taken from the AspiringDocs.Com campaign described earlier. The NSGC could feature a “one stop shop” approach by creating a website that provides potential applicants with tips on how they could best prepare for a genetic counseling career, application information, guidance on financial assistance, and access to a live “community” that will allow them to interact with students, program directors and professionals.

While this approach could be costly, private funding institutions such as the Robert Wood Johnson Foundation (RWJF) have made available granting mechanisms for online efforts to diversify the health workforce through its ExploreHealthCareers.org initiative (www.explorehealthcareers.org). In 2007, the organization announced a sizable grant awarded to the American Dental Education Association (ADEA) to administer and expand a free interactive health career website explaining dental careers and providing easy access for potential students seeking information.

The Educational Pipeline

Efforts to enhance awareness about a genetic counseling career among underrepresented minorities should start not only in high school, but earlier in middle and even elementary school. The Bureau of Health Professions, housed within the Health Resources and Service Administration (HRSA) developed a comprehensive site through the “Kids Into Health Careers” initiative (Gilchrist and Rector 2007). Realizing that career aspirations and one’s career identity begins to develop as early as the second grade, the Kids Into Health Careers initiative has in place engaging curricula for educators, students and their parents in English, Spanish and other languages.

Parent involvement in students’ education has been highly predictive of enrollment in higher education (Gilchrist and Rector 2007). In lower socioeconomic groups, parents may be unable to serve as “pathfinders” for their children, who in turn need to rely heavily on school counselors and teachers for career guidance. Career counselors may not be well informed about health careers options beyond the

most visible careers in nursing and medicine. To that end, genetic counselors can also make themselves available to give career day presentations at various schools in their areas, with an emphasis on those with a diverse student body.

Post-Secondary Recruitment Strategies

Responses related to recruitment by Oh and Lewis’ (2005) sample, and data from the diversity survey suggest that recruitment strategies in college may be quite successful in attracting people into the genetic counseling profession. The profession should continue to devote efforts to recruit college students to the genetic counseling profession, and they will do well to target colleges with high minority enrollment as well as community colleges. The AAMC’s data showing an increase in minority students choosing biology and science majors are encouraging and should be capitalized; specifically, freshman and sophomore biology and psychology major students should be targeted and mentored to apply for genetic counseling programs.

Importantly, recruitment should expand to students with non-traditional career paths, such as those who are enrolled in programs that combine the 2 and 4 year college experience and health professionals seeking a career change. Another untapped resource is foreign-trained health professionals who may not be able to practice in their original vocations because of accreditation issues, and who are considering career changes. These individuals are by-or multi-lingual and their multicultural skills could prove to be a great asset to the profession as well as identify a new purpose for themselves.

Mentoring

Faculty and peer mentoring is key to assisting students to thrive in an academic climate in which they are underrepresented. Importantly, the fact that the NSGC has few African-American and Hispanic members makes for a professional climate that likely is challenging to members from these backgrounds. Minority students could be paired with diverse faculty and those who share their interests from related fields in their institution or with genetic faculty from other institutions in the event that such mentors are in short supply in their own institutions. Lastly, students can be encouraged to join diverse student groups in their institutions for peer support.

Efforts by Program Directors

It is important that program directors remain current regarding minority recruitment literature, best practices and national standards. They should continually explore

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