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Caring for the Genetics Services Needs of Children and Families: Exploring the Information Needs of Healthcare Providers

Mary S. Tijerina, PhD, Katherine Selber, PhD and Virginia Rondero Hernandez, PhD

Introduction

Current and emerging advances in the field of genetics have impacted the nation's delivery of healthcare, and increased the demand for knowledge and resources to address the needs identified by an array of new testing and risk assessment technologies (Genetic Alliance, 2006; National Association of Social Workers, 2003; National Society of Genetic Counselors, 1996-2006). These advances also imply the need for a systematic approach to redefining both genetics services and delivery systems as well as the need to emphasize the importance of integrating genetics into the health and allied health fields. Genetic services include review of family and medical histories, physical examinations, psychosocial assessments, laboratory testing, counseling, education, and referral for appropriate management. For families with genetic conditions, a multidisciplinary response involving physicians, clinical geneticists, genetic counselors, social workers, nutritionists, early childhood specialists and others is often warranted due to needs that encompass medical, educational, legal, mental health, and other bio-psychosocial dimensions. Within this multidisciplinary approach, common roles and functions of social workers in genetics services include psychosocial assessment, psychosocial counseling for purposes of coping and adaptation, and referral for other available and supportive services. Additionally, social workers and other health practitioners can contribute to the genetic services delivery system by advocating for a more ecological, holistic framework for genetic services, including consumer-oriented intervention strategies, mobilizing community resources, engaging multiple stakeholders, advocating for policy changes, and collaborating with an array of disciplines to more effectively design and execute consumer friendly services. Part of this program development strategy encompasses the issue of training and preparing healthcare personnel to be responsive to the need for changes in the way genetics services are organized and delivered as well as to prepare healthcare professionals to serve persons with an array of disorders and disabilities.

Leadership for the development of genetics services capability in the U.S. has historically come from the federal government though the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration (HRSA). However, the organization of genetics services varies from state to state. In the state where the present study was conducted a recent series of organizational shifts resulted in a decentralized, highly fragmented system in which genetics services were organized in several administrative structures and programs that lacked overall coordination and were not family-centered (Selber, Rondero Hernandez, Tijerina, Heyman & Sallee, 2006). In order to move toward a comprehensive, coordinated, consumer-based system of genetics services, it is critical to conduct a systematic analysis of the concerns, needs, and priorities of various stakeholder groups having the greatest investment in the delivery of these services (USDHHS, 2000). One such stakeholder group, medical and allied health providers of care to individuals and families affected by genetic conditions, is the focus of the present study.

This article reports on the results of an exploratory survey that was part of a two-year research project contracted by a state health authority to collect data for developing a statewide, family-centered strategic plan for genetics services. Specifically, the purpose of the survey was two-fold: (1) to gather practitioners' perceptions about the existing genetics service delivery sys-

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tem, and (2) to identify knowledge and information needs important to practitioners' ability to care for individuals and families with suspected or diagnosed genetic conditions. A better understanding of practitioners' knowledge needs can help improve the system by identifying target areas for education and training efforts. This article also covers implications for services and policy development.

Background

Many professionals in the field of disability are skeptical of genetics. This skepticism is likely due to the history of the use and abuse of genetic terminology and information. In 1883, Galton introduced the term "eugenics," referring to the purported improvement of the population by selecting only its best specimens for breeding. The ensuing eugenics movement was driven by social, ethnic, and economic prejudices rather than humanitarian or scientific concern (Gillot, 2001). During the first half of the 20th century, the movement was manifested in the U.S. through the practice of sterilizing those considered "feebleminded" and "shiftless" as well as through the passage of laws denying entry to immigrants with what were thought to be of undesirable genetic backgrounds (Collins, Green, Guttmacher & Guyer, 2003).

Unlike eugenics, the Human Genome Project has sought to translate genome-based science into new and more effective strategies for the prevention, diagnosis, and treatment of diseases and disorders (Collins, et al., 2003). The Human Genome Project has led to advanced understanding of basic genetic processes, discoveries of the genetic basis for hundreds of disorders, and increased technologies such as genetic tests (Skinner & Shaffer, 2006). Bailey & Powell (2005) note that as parents and practitioners begin to learn more about genetic disorders, they will need (1) more comprehensible information about genetics in general and specific disorders in particular, (2) the ability to speak the language of genetics, (3) access to a wide range of information and support, (4) assistance in sorting through information of varying quality and authority, and (5) assistance in determining the most effective treatment for a particular disorder.

Increased consumer demand for genetics information and consultation would also suggest that medical practitioners are increasingly expected to be knowledgeable about genetics. According to the American Medical Association, 50 percent of Americans report they are somewhat or very likely to take advantage of genetic testing and 72 percent believe that their primary care physicians can interpret genetic test results (Mitka, 1998, cited in Karanjawala & Collins, 1998).

However, research suggests that this confidence may be misplaced. General practitioners report difficulty assessing genetic risk of their patients as well as a tendency to overestimate genetic risk (Fry, Campbell, Gudmunsdottir, Rush, Porteous, Gorman & Cull, 1999). Other studies have found that fewer than 20 percent of patients actually received appropriate genetic counseling (Giardiello, Brensinger, Petersen, et al., cited in Karanjawala & Collins, 1998). General practitioners also report a lack of confidence in their own ability to cope with increased demands for genetics advice (Watson, Shickle, Qureshi, Emery & Austoker, 1999). A contributing factor may be the overwhelming quantity of genetics data being generated, particularly in some fields, such as cancer research. The volume of information and the speed at which it is being generated can challenge the capacity of most physicians to integrate and apply the information in their clinical practice (Taylor & Kelner, 1996; Kapur, Higgins, Doughty & Kallen, 1983).

A lack of professional training in genetics may be another factor in physicians' lack of confidence in providing genetic advice. Stephenson (1998) found that many practicing physicians have limited genetics training. Indeed, medical practitioners who do not specialize in genetics report a lack of confidence in their ability to provide such services due to limited knowledge of clinical genetics (Emery & Hayflick, 2001; Geller & Holtzman, 1995; Watson et al., 1999). Among general practitioners, lack of confidence in their role has been found to result in inappropriate referral practices (Fry, et al., 1999).

Even when physicians do report having adequate knowledge of genetics, their self-assessment does not always carry over to their

clinical practice. Hunter, Wright, Cappelli, Kasaboski & Surh (1998) found that although a majority of physicians reported adequate knowledge of genetics, only a minority felt sufficiently confident to provide genetic counseling for simple genetic scenarios. Level of knowledge was found to be an important influence on referrals to genetic services and on attitudes toward genetic screening and prenatal diagnosis. Furthermore, the study found that physicians had relatively poor knowledge of available services. Thus, in addition to genetics knowledge and enhanced clinical skills, knowledge of available resources and appropriate referral procedures may affect practitioners' ability to perform their roles effectively.

Other professions also report the need for more genetic information. Disability service professionals have frequently cited the need for more information on treatment and outcomes across a variety of services accessed by people with disabilities (Fox & Kim, 2002). In a web-based survey of staff of organizations that were likely to provide collateral referrals for individuals and families with genetic conditions, key informants reported a lack of information regarding community resources for serving individuals with genetic conditions and a lack of information regarding genetic conditions (Selber, et al., 2006). Social workers have also identified the need for more information and education in order to be more effective in service provision in this field (NASW, 2003). Results of a national study using a random sample of 3,600 members from six professional organizations—including social workers who worked with clients with genetic conditions—revealed that respondents had little confidence in their ability to provide genetic services.Most had little or no education in genetics, and two-thirds identified a need for continuing education. Fewer than 30% of the respondents felt that they were suitably equipped to help their clients make decisions about genetic testing. These findings further suggest the importance of training all allied health professions, including social workers and psychologists who work with individuals with genetic conditions and their families (Lapham, Kozma, Weiss, & Benkendorf, 2000).

Health officials and other public policy makers are faced with integrating the dynamic field of genetics into relevant policies and programs so that all populations can gain from genetic technology advances. It is, therefore, essential that all health professionals have the knowledge, skills, and resources to integrate new genetic knowledge effectively into practice. This requires an understanding of the gap between existing genetic practice and genetics education of health and allied health professionals.

Method

In order to survey a range of professionals about levels of genetics knowledge, web-based technology was selected because it offered both accessibility and efficiency in data collection (Flowers, Bray, & Algozzine, 1999; Sheehan & McMillan, 1999). Survey SolutionsÓ, a commercial software package produced by the Perseus Development Corporation, was selected based on its ease of use, low cost, and availability of technical support. In addition, because the software does not deposit "cookies" on survey respondents' computers, anonymity of responses can be assured.

Instrument Development

Survey domains were derived from a review of the literature and subsequently prioritized in collaboration with the state health authority for development of the final survey instrument. Survey items focused on the types and levels of knowledge that practitioners believed were important to make effective use of the current genetic service delivery system, specifically knowledge related to making appropriate referrals for genetic services, e.g., knowing when to refer patients for services and where to refer them. Other domains included practitioners' sources of genetic information, perceptions about the availability of genetic services, barriers encountered in referring patients to genetic services, and demographic items about respondents and their professional practice. The 30-item instrument consisted of closed- and open-ended questions.

Sampling Design

The population of interest was medical and

allied health professionals in a large southwestern state who provide care to persons with suspected or diagnosed genetic conditions. Specifically, the study population included physicians (primary care physicians, obstetrician/gynecologists, pediatricians, and clinical geneticists), nurses, genetic counselors, nutritionists, physical/occupational therapists, and social workers.. The absence of a sampling frame for this population prevented the use of a probability sampling design, limiting the generalizability of the study. Nevertheless, given the exploratory nature of the study, a non-probability sampling strategy was considered appropriate for the research. A purposive, progressive sampling technique was used to identify potential respondents via several sources: 1) recommendations from a network of principal contacts (physicians and allied health professionals representing regional or state leadership in the field of genetic services; 2) referrals from the state health authority; 3) group email lists of health care providers; 4) membership lists of professional associations or organizations; and 5) web searches of major medical provider organizations. Email addresses for potential respondents obtained through these various sources were pooled and duplicate addresses eliminated, resulting in a distribution list of 576 individuals.

Implementation

An invitation to complete the online survey was emailed to each person on the distribution list. The invitation described the purpose of the study, benefits of participation, criteria for selection of recipients, length of time required to complete the survey, and assurances of response anonymity. Recipients were encouraged to forward the invitation to colleagues and other practicing medical and allied health professionals meeting the stated criteria.

The direct email invitation included a link to the URL address of the survey, which was posted on the website of the research institute conducting the study. The electronic invitation announced that the survey would be online for ten days. The timeframe was subsequently extended for five days due to a low response rate; a follow-up email message was sent announcing the extension, encouraging response, and providing another link to the survey.

Results

Respondents

A total of 86 usable responses were received. Based on the number of direct invitations emailed (n=567), this represents a response rate of 15 percent. The majority of respondents were white, non-Hispanic (67 percent, n=59) males (78 percent, n=67) practicing in an urban area. Geographic location was approximated by asking respondents to indicate the state health region in which their practice was located. Two thirds of the respondents (n=48) reported their practice was located in a region corresponding to the location of a major, urban, teaching hospital.

The sample was heterogeneous with regard to fields of practice, time in practice, and genetics training. As shown in Table I, the largest group of respondents indicated their professional group membership as genetics counseling (17 percent, n=15) followed by social work (15 percent, n=13), clinical genetics (12 percent, n=10), and pediatrics (11 percent, n=9). Smaller numbers of respondents reported fields of practice such as early childhood intervention, health education, public health, and genetics research.

The majority of respondents (56 percent, n=48) had been in professional practice less than five years. In terms of their level of professional preparation in genetics, more than half of the respondents (51 percent, n=44) reported having completed more than five years of formal academic training in genetics (i.e., genetics content included in academic curriculum). This reported level of formal academic training in genetics is attributed to the variety of training some of the respondents had received in genetics specialties. More than one-third (36 percent) of the sample reported genetics as the focus of their professional practice including clinical genetics (n=10 or 11.6 percent, genetic counseling (n=15 or 17.4 percent), genetics research (n=3 or 3.5 percent), clinical cytogeneticist (n=2 or 2.3 percent), and molecular genetics (n=1 or 1.2 percent).. Another 23 percent (n=20) of the sample, including the

subgroup of social work respondents (n=13 or 15 percent), reported having less than three years of formal academic training in genetics.

In terms of the proportion of their practice that is spent on genetic conditions, one-third of the sample (n=28) estimated that more than 90 percent of their professional practice pertained to genetics, while a slightly smaller proportion, 30 percent (n=26), estimated that less than 10 percent of their practice pertained to genetics and 17 percent (n=15) estimated between 10 and 25 percent of their practice is devoted to genetic conditions.

Types and Levels of Knowledge Related to Genetic Services

Levels of genetic knowledge were assessed by presenting respondents with a list of 15 items (see Table II) and asking them to indicate how knowledgeable they believed practitioners are about each item. Response options were based on a scale of 1 to 5 where 1= "Not at All Knowledgeable," and 5 = "Very Knowledgeable." A mean rating was calculated for each item. (See Table II.) Items with the highest mean ratings were "Recognizing the symptoms of common genetic conditions" (3.4), "Taking adequate family histories" (3.2), "Identifying conditions for which genetics counseling is appropriate" (3.1), and "Knowing when to refer patients for genetics services" (3.0).

Subsequent to calculation of the mean ratings, response categories on either side of the "No Opinion" mid-point on the five-point rating scale were collapsed, resulting in two broad classifications: "Very or Somewhat Knowledgeable" and "Not Very or Not at All Knowledgeable." (See Table II.)see table PPPPractitioners were perceived as "Very or Somewhat Knowledgeable" about "Recognizing the symptoms of common genetic conditions" (69 percent, n=59), "Knowing where to find information about genetic conditions" (57 percent, n=48), "Taking adequate family histories" (54 percent=46), "Identifying conditions for which genetics counseling is appropriate" (54 percent, n=45), and "Knowing when to refer patients for genetic services," (50 percent, n=42).

Elements about which practitioners were perceived as "Not Very or Not At All Knowledgeable" included "Putting family history information into heredity patterns" (71 percent, n=60), "Maintaining currency with the genetics literature" (68 percent, n=56), "Recognizing psychosocial problems that require referral" (68 percent, n=56), "Knowing the limitations of genetic testing" (59 percent, n=49), "Knowing how to interpret genetic testing results" (59 percent, n=50), "Helping patients to understand test results" (56 percent, n=47), and "Knowing what services are available for persons with genetic conditions" (54 percent, n=46).

Relative Importance of Types of Knowledge

Following their ratings of levels of knowledge perceived for each of the 15 elements, respondents were also asked to (1) select from the same list of 15 elements the five most important types of genetics knowledge practitioners should have and (2) rank those five items from "Most Important" to "Least Important."

All items selected as being among the five most important types of knowledge were then weighted on the basis of the relative ranks assigned by individual respondents. Items ranked as "Most Important" received the greatest weight and those ranked as "Least Important" received the lowest weight. The resulting weighted scores were then used to create an overall rank-ordering of the importance that respondents assigned to each of the elements of genetics knowledge. (See Table III.) Elements perceived by respondents as the most important types of knowledge for practitioners to possess were the following: "Recognizing the symptoms of common genetic conditions" and "Knowing when to refer patients for genetic services," followed by "Identifying conditions for which genetics *counseling* is appropriate" and "Identifying conditions for which genetics *testing* is appropriate."

Additional Genetics Knowledge Needs Identified by Respondents

In addition to the list of 15 elements of genetics knowledge presented by the survey, respondents were invited to respond to an open-ended item asking them to identify other types of knowledge important for practitioners who provide services to individuals and families with suspected

or diagnosed genetic conditions. Thirty-one respondents (36 percent) cited a variety of additional knowledge needs. The largest number (n=14) identified knowledge needed for referring patients to genetic services, e.g., knowledge about available resources and supports for specific genetic conditions, how to access and/or pay for these services, and how to prepare families for what to expect from an office visit with a genetic practitioner compared to "the typical doctor's appointment." Six responses cited a need for knowledge related to specific genetic conditions, e.g., "knowledge of genetic syndromes" and "probabilities of transmission." Other knowledge needs related to family and cultural issues, e.g., how to manage "implications of genetic conditions" such as emotional repercussions on the family; how to effectively communicate information about diagnosis and prognosis of genetic conditions to families; and knowledge about how to handle cultural and educational differences between practitioners and families.

Sources of Genetics Information

Respondents were asked to indicate their most likely source of information about genetic services, both in terms of overall knowledge and with regard to specific case consultation. With regard to overall genetics knowledge, the most commonly reported sources were "Genetic Specialists" (23 percent, n=20), the "Internet" (23 percent, n=20), and "Continuing Education/Conferences" (22 percent, n=19). Less likely sources were "Books or Journals," (14 percent, n=12) and "Professional Associations," (7 percent, n=6). With regard to information for specific case consultations, almost three-fourths of respondents (67 percent, n=58) reported that they would turn to a genetic specialist as their primary source of genetics information.

Service Availability and Access

Respondents were asked whether they believed genetic services were, for the most part, available for persons residing in their geographic area. (For purposes of preserving anonymity, "geographic area" was defined as the state health service region in which respondents were practicing.) Response options were "Yes," "No," and "Somewhat." The majority of respondents (61 percent, n=48) reported that services are available in their region. Another 14 percent (n=11) indicated that services were "Somewhat" available, for a total of 75 percent of respondents who believed that at least some level of services was available in their geographic area.

An open-ended item invited respondents to offer comments regarding the availability of genetics services in their regions. Twenty respondents offered comments, with the majority citing uneven geographic distribution of services as an issue. Lack of services in rural areas was perceived by respondents as presenting extra burdens for individuals and families in terms of cost, time, and effort required for travel to obtain services. For example, one respondent commented: *"[A clinical geneticist] comes to [our city from a metropolitan area] but it is constantly a budget struggle.... We are anxious that we may lose these services. If a medical geneticist doesn't come to [our city], many of the people needing this service will not be able to access it due to costs, travel limitations, and lack of local support to see a geneticist.*"

Five respondents commented about socioeconomic factors that limit patients' access to services; four respondents specifically identified lack of insurance coverage or insurance exclusions for genetic services as barriers to service access. Examples of these comments are:
"[Genetics services are not available] for those with little/no insurance, or to those with insurance companies of providers that won't refer to geneticists. The poor, lower educational level patient does not have access that is understandable and reachable to them."

Barriers to Practitioners' Ability to Make Referrals for Genetic Services

Respondents were asked if they encountered barriers in referring individuals and families to genetic services; response options were "Yes," "No, and "Somewhat." Although 46 percent (n=35) reported that they did *not* encounter such barriers, 51 percent indicated they had experienced barriers to some degree (35 percent responding "Yes," 16 percent "Somewhat") in re-

ferring individuals and families for genetic services.

An open-ended item invited participants to comment on perceived barriers to making referrals for genetic services. Many of the responses to this question overlapped with comments regarding service access described above. Of the 24 respondents who offered open-ended comments about perceived barriers to making referrals for genetic services, the largest number (n=10) cited lack of financial resources to cover costs of services. Examples of such comments include: *"In our genetics practice, it is difficult to get appropriate genetic testing for patients on Medicaid and private insurance.*" and "*Many insurance plans will not cover genetic services and it takes a lot of time and effort to appeal denials of coverage."*

Additional barriers to referral included practitioners' cultural competency and lack of knowledge about what services are available. The following are examples: *"Barrier is knowing (the) most current information, most current location of services, access to specialist if problem is suspected."* and *"Don't know but one geneticist who I consider a practicing current and culturally aware of barriers sort of* [sic] *practitioner and they are at the medical school and thus not very accessible to the public! So where do I find these people?"* and *"Not knowing where the services are and the length of time it takes to get someone seen."*

Final Comments

At the conclusion of the survey, respondents were provided a final opportunity to comment about any other information that might help the state health authority understand the types of knowledge needed by service providers to enhance genetic services for individuals and families. Twenty-one participants provided qualitative comments centering around four themes: (1) suggested educational approaches; (2) specific service needs; (3) barriers to utilization of existing services; and (4) cost of services or financial concerns.

Suggestions for education of practitioners included enhancing the professional school curriculum and making genetics education available through continuing education programs and local lectures, for example: *"As a clinical geneticist, I would like to see more time allotted in professional schools to teach genetic concepts from which point the doctor or nurse will be better equipped to understand complex genetic testing issues."* and "*Need more local lectures [on how] to identify patients to increase genetic referrals."* and *"Could [the state health authority] hold in-services for primary providers (i.e., family practice docs, ob/gyns, pediatricians) to educate them about genetics as a specialty and how we genetics people can be of service to them?"*

Service needs identified by respondents included increased numbers of genetic counselors and caseworkers, increased use of technology for earlier diagnosis, additional low-cost services for persons with limited financial resources, and public awareness and information about common genetic conditions, including what persons can expect from genetic counseling. The specific types of service needs identified were networking/support groups for families, case management, psychological counseling and support services, and resources for general information and education, particularly web-based resources.

Cost-related issues included budget needs for support staff or allied health personnel and the lack of financial incentives for practitioners to enter the field of medical genetics. Additional comments concerning barriers to service echoed previously identified issues such as lack of awareness of available services, lack of knowledge about how to access services, and the uneven geographic distribution of services across the state. These issues are crystallized in the following quote: *"Obviously there are barriers to this specialty which include the limited resources of the patients, the large area that comprises our state, and an overall lack of awareness about (A) what genetic services are (B) where they are and (C) how to get patients hooked up with them."*

Discussion

This study used a web-based survey to explore the genetics knowledge and perceptions of medical and allied health professionals about the existing statewide genetic services delivery system and factors that promote or inhibit their ability to utilize this system in providing care for individu-

als and families with suspected or diagnosed genetic conditions. Consistent with the goal of exploratory studies, the aim was to provide a beginning understanding of variables important to this particular sample's use of the statewide genetic services system rather than to generalize the findings to a broader population. Although a limitation of the study, this lack of generalizability is a result of the non-probability sampling strategy necessitated by the lack of a central mechanism for readily identifying the study population.

While disappointingly low, the 15 percent response rate obtained in this study falls within the wide range of 6 to 75 percent response rates that has been reported for electronic surveys (Bauman & Airey, 2000). Among the reasons cited for the lower response rates to electronic surveys is the relative ease with which such surveys can be ignored, discarded, or forgotten, compared to traditional mail surveys that physically appear on recipients' desks and serve as reminders to respond (Yun & Trumbo, 2000; Sheehan & McMillan, 1999). The low response to this survey of medical and allied health practitioners is also consistent with the low response rates that have been reported for physicians' surveys even when traditional, postal mail formats are used. Physicians' non-response to mail surveys has been attributed to the volume of questionnaires they receive and their perception of continually being asked for information with little or no return (MacPherson & Bisset, 1995).

Despite the low response rate, the study meets its intended aim of providing a preliminary understanding of the participants' perceptions about types and levels of genetics knowledge important to the use of the existing system of services. While the small numbers of respondents in the various professional categories unfortunately resulted in the inability to make meaningful comparisons between or among the various disciplines, the findings nevertheless begin to identify variables that can serve as the basis for future research involving larger, probability-based samples.

The respondents' perceptions of practitioners as knowledgeable about risk assessment (i.e., recognizing the need for genetic services and knowing when to refer patients for specialized services) but less knowledgeable about the clinical application of genetics information (e.g., evaluating family history information, interpreting genetic test results, and communicating test results to patients) are consistent with those of Hunter et al. (1998), who found that while a majority of physicians reported having adequate knowledge of genetics, only a minority of them actually felt confident enough to provide genetic counseling. This perceived lack of confidence would suggest increased referrals of children and families to genetic specialists. However, more than half of respondents in this study perceived other practitioners as "Not Very or Not at All" knowledgeable about services available for persons with suspected or diagnosed genetic conditions. Lack of knowledge about available resources suggests that families and children may not be receiving the referrals and services they need. This is consistent with other findings in the overall research project in which staff of agencies providing collateral contacts and referrals responded that they were not aware of community resources or knowledge of the needs of individuals with genetic conditions (Rondero Hernandez, Selber & Tijerina, 2006; Selber, et al., 2006).

Given that two-thirds of respondents reported they were practicing in regions corresponding to the location of major urban areas and teaching hospitals, it is not surprising that the majority reported that at least some level of genetic services was available in their regions. Nevertheless, qualitative responses cited the uneven geographic distribution of genetics services and the consequent burdens this placed on families living in rural areas. In addition to uneven geographic access, lack of services for economically disadvantaged, uninsured and underinsured families were identified as barriers to practitioners' ability to make referrals as well as to families' ability to access services. These findings suggest that even if the types of services currently available in some areas of the state were expanded into rural areas and marketed to increase practitioners' awareness of their availability, cost factors could potentially continue to function as a barrier to services. Expansion of services into underserved areas of the state would continue to be beyond the reach of

many poor and uninsured families. Even among families with the means to obtain insurance, research indicates that families are being refused health insurance because of genetic inheritance (Lapham, Kozma & Weiss, 1996; Genetic Alliance, 2006). According to Oktay (1999), this situation could eventually result in an underclass of individuals who are unable to obtain health insurance due to genetic susceptibility (Oktay, 1998).

Taken together, the findings regarding practitioners' lack of knowledge about available services and their preference for expedient, computer technology-based sources of information suggest the need for increased availability of web-based training and resource information. For example, a state-wide, web-based resource directory that would offer readily available information about the continuum of genetic services available by geographic area would be valuable to practitioners and consumers alike. Similarly, computer- or web-based educational materials may be the most effective medium for disseminating genetics information to assist physicians in making referrals to genetic services. Examples of educational materials that could be disseminated in this fashion include well-articulated referral guidelines, information about specific genetic conditions, and information summaries or case histories to guide clinical decisions. Also needed are educational materials that focus on skills development such as interpreting results of genetic tests and communicating genetics information to individuals and their families.

The results of this exploratory survey also have implications for social work education and practice. In social work education, few schools include genetics content in courses within the professional foundation or concentration curriculum. Unless there is a health care concentration or specialty within the program, information and skills in this area frequently are not available to most students. Although genetics can play a critical role in the behavior and development of all individuals and families served by social workers, until recently, only those students electing field placements in this specialty can hope to obtain information and develop skills in this area. The new *NASW Standards for Integrating Genetics into Social Work Practice* (2003) may help promote curriculum advances in this area. The reported perceptions of practitioners as less than knowledgeable in recognizing psychosocial problems requiring referral and in knowing what resources are available to address psychosocial needs of individuals and families suggest an important role for social workers. As multidisciplinary team members in situations involving genetic issues, social workers must be prepared to fulfill roles, including referral source and service broker, educator and facilitator of decisions, provider of long-term psychosocial supports and services, advocate, and policy shaper (Scheyett & Strom-Gottfried, 2004). Without specialized training, social workers cannot assume the role of genetic counselors; however, they can make important contributions within the scope of social work practice. Knowledge and skills for case-finding and biopsychosocial assessment, treatment planning, and linking individuals to appropriate, available services are fundamental components of social work practice. Adding genetics content to pre-professional and continuing social work education programs would enhance social work practitioners' effectiveness in providing psychosocial and support service referrals to persons with suspected or diagnosed genetic conditions.

Social workers must become more aware of the ethical, legal and psychosocial implications related to genetic diagnoses, genetic testing, and genetic research if they are to empower individuals and families to access available services and make decisions for themselves. Similarly, educating medical and allied health practitioners' about the psychosocial implications of having a suspected or diagnosed genetic disorder can enhance their ability to identify problems requiring referral and make more effective use of the existing service delivery system, thereby enhancing the service experience for individuals and families affected by genetic conditions.

As the health needs of children and families with genetic conditions become more complex and funding is realigned and reprioritized, it is essential that social workers and health professionals are able to work in collaborative and integrated models of care. Accomplishing this will

require adjustments in educational initiatives in the field of genetics and integrating this information into health and allied health curricula and continuing education programs. Leadership in this area requires a collaborative and interdisciplinary effort to close the gap between practice and education in order to capitalize on the advances in genetics care.

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Table I
Sample Characteristics

Variable	Number	Percent
Professional Group		
Pediatrics	9	10.5
Obstetrics	2	2.3
Clinical Genetics	10	11.6
Genetic Counseling	15	17.4
Social Work	13	15.1
Nursing	6	7.0
Nutrition	10	1.2
Other (early childhood specialist, health educator., public health, research)	24	27.9
No Response	6	7.0
Total	86	100.0
Years in professional practice		
Less than five years	48	55.8
Five to ten years	12	14.0
More than 10 years	15	17.4
No Response	11	12.8
Total	86	100.0
Percentage of current practice pertaining to genetics		
Less than 10%	26	30.2
10% - 25%	15	17.4
26% - 50%	2	2.3
51% - 75%	4	4.7
More than 90%	28	32.6
No Response	11	12.8
Total	86	100.0
Years of formal academic training in genetics		
Less than three years	20	23.3
Three to five years	11	12.8
More than five years	44	51.2
No Response	11	12.8
Total	86	100.0

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Table II

Ratings* of Practitioners' Levels of Knowledge About Genetics Services

Type of Knowledge	No. Responding	Very/Somewhat Knowledgeable		Not Very/Not At All Knowledgeable		Mean Rating
		No.	Pct.	No.	Pct.	
Recognizing symptoms of common genetic conditions (N=85)	85	59	69.4	23	27.1	3.4
Knowing when to refer patients for genetic services (n=84)	84	42	50.0	35	41.7	3.1
Identifying conditions for which genetics *counseling* is appropriate	84	45	53.6	32	38.1	3.1
Identifying conditions for which genetics *testing* is appropriate	85	42	49.4	36	42.4	2.6
Knowing what services are available for persons with genetic conditions	85	28	32.9	46	54.1	2.6
Taking adequate family histories	85	46	54.1	33	38.8	3.2
Helping patients to understand test results	84	26	31.0	47	56.0	2.6
Knowing where to find information about genetic conditions	85	48	56.5	31	36.5	3.2
Knowing the limitations of testing	83	25	30.1	49	59.0	2.5
Assessing the patient's/family's understanding of information provided	83	33	39.8	41	49.4	2.8
Knowing how to interpret genetic test results	85	25	29.4	50	58.8	2.6
Putting information gathered into heredity patterns	85	21	24.7	60	70.6	2.4
Maintaining currency with the genetics literature	83	15	18.1	56	67.5	2.2
Making decisions about when follow-up is necessary	84	35	41.7	39	46.4	2.9
Recognizing psychosocial problems that require referral	84	34	40.5	40	47.6	2.8

* Ratings based on a 5-point scales where 1="Not at All Knowledgeable," 2="Not Very Knowledgeable," 3="No Opinion," 4="Somewhat Knowledgeable," and 5="Very Knowledgeable."

Due to the small sample size and for ease of reference, the two categories on either side of the "No Opinion" response were collapsed, resulting in two broad categories: "Very/Somewhat Knowledgeable" and "Not Very/Not at all Knowledgeable."

Table III

Weighted Ranking of Genetic Services Identified Among Top Five Most Important

Type of Knowledge	Weighted Score*	Rank Order Among Top 5
Recognizing the symptoms of common genetic conditions	233	1
Knowing when to refer patients for genetic services	232	2
Identifying conditions for which genetics *counseling* is appropriate	128	3
Identifying conditions for which genetics *testing* is appropriate	115	4
Knowing what services are available for persons with genetic conditions	76	5
Taking adequate family histories	59	6
Helping patients to understand test results	51	7
Knowing where to find information about genetic conditions	40	8
Knowing the limitations of testing	37	9
Assessing the patient's/family's understanding of information provided	36	10
Knowing how to interpret genetic test results	29	11
Putting information gathered into heredity patterns	25	12
Maintaining currency with the genetics literature	24	13
Making decisions about when follow-up is necessary	19	14
Recognizing psychosocial problems that require referral	12	15

*Weighted score was calculated using total numerical values of each item ranking where 5=Most Important to 1=Least Important.