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Genetic Service Delivery: Infrastructure, Assessment and Information

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Abstract
Identification of genomic determinants of complex disorders such as cancer, diabetes and cardiovascular disease has prompted public health systems to focus on genetic service delivery for prevention of these disorders, adding to their previous efforts in birth defects prevention and newborn screening. This focus is consistent with previously identified obligations of the public health system as well as the core functions of public health identified by the Institute of Medicine. Models of service delivery include provision of services by the primary care provider in conjunction with subspecialists, provision of services through the medical home with co-management by genetics providers, provision of services in conjunction with disorder-specific treatment centers, and provision of services through a network of genetics clinics linked to medical homes. Whatever the model for provision of genetic services, tools to assist providers include facilities for outreach and telemedicine, information technology, just-in-time management plans, and emergency management tools. Assessment tools to determine which care is best are critical for quality improvement and development of best practices. Because the workforce of genetics providers is not keeping pace with the need for services, an understanding of the factors contributing to this lag is important, as is the development of an improved knowledge base in genomics for primary care providers.

Introduction

During the 20th century, achievements in public health resulted in dramatic improvements in the health and life expectancy of people throughout the world [1]. These improvements were largely the result of immunization programs, better sanitation practices, advances in occupational safety, and, more recently, the development of educational programs to combat behavioral risk factors, such as smoking and poor dietary habits [2]. Thus past successes in public health built on strategies to combat disease determinants that appeared to originate outside the body [2]. Advances in human genetics allow this focus to shift toward host-specific factors modified by environmental exposure, and a vision for genetically based individualized prevention strategies becomes feasible. Complex disorders, such as cancer, diabetes, heart disease, and stroke are now understood to have genomic determinants. Identification of these genomic determinants in individuals within populations can lead to changes in public health policy including promotion of prevention

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strategies. In addition to approaches to these complex disorders, the public health community has taken responsibility for programs in birth defects prevention [3, 4], newborn screening [5, 6] and development of genetic services capacity [7].

This article will review the functions and obligations of the public health system, emphasizing their relation to the delivery of genetic services for the public's health. We will then discuss several models for the delivery of genetic services, including tools that may be of use in all potential service delivery models. Examples of quality improvement tools for assessing genetic services will be provided, and the benefits of information networks that can enhance both service delivery and evaluation will be discussed.

Genetic Determinants and the Public's Health

Numerous studies on diseases of major public health importance (e.g. cancer, heart disease, diabetes, and stroke) consistently show that the odds of developing 1 of these conditions are significantly increased by having 1 or more close relatives with the disease [8–11]. These findings suggest that family history can serve as a powerful tool in identification of at risk individuals for prevention strategies [12].

In addition, Cheng et al. [13] have identified at least 4 types of genetic testing that will be used in practice in the future. These are: expansion of universal screening for diagnosis of relatively rare diseases, risk-based genetic screening for diagnosis of more common conditions (more than 50% of SN hearing loss cases have a genetic cause, many of which can be identified through use of mutation analysis [14]), screening tests to assess predisposition to future health problems (e.g. genetic tests to assess a patient's risk for otitis media [15, 16]), and pharmacogenetic testing to assess effectiveness or adverse effects of medications.

While these genetic tools may expand the traditional risk-based individualized approach of medicine, population approaches must also be strengthened simultaneously to ultimately achieve improved health outcomes [17] for all segments of the population.

Public Health Functions and Obligations

Harrell and Baker [18] developed a list of fundamental obligations of the public health system, including prevention of the spread of disease, protection against environmental hazards and promotion of healthy behaviors. It seems clear that prevention strategies can be used to reduce the morbidity and mortality of chronic disorders with genetic risk factors. Protection against certain environmental hazards is a key component of this strategy, and promotion of healthy behaviors is a basic mechanism for effecting this protection.

In its landmark report *The Future of Public Health,* the Institute of Medicine defined 3 core functions of public health: assessment, policy development and assurance [19]. To accomplish these core functions, the US Maternal and Child Health Bureau, Health Resources and Services Administration and the Department of Health and Human Services developed a 4-tier pyramid model to outline the essential components of a public health system [20]. These are infrastructure building services, population-based services, enabling services, and direct health services [7] (fig. 1). These components, when considered in the context of the 3 core public health functions defined by the Institute of Medicine, delineate the roles of health care providers and the public health system in providing genetic services [7] (fig. 2).

Accepting that population approaches are needed to address genetic risk factors, and recognizing that genetic service delivery must exist in the context of serving all of an individual's health care needs, what are the systems of care that can be envisioned to meet both of these sets of requirements?

Primary Care Provider Delivers Many Services

Analyses by Starfield et al. [21] of potential systems of care to address genetic discoveries suggest that primary care-centered systems are most likely to be cost-effective and improve health [13]. Roles of clinicians include identification of individuals with conditions requiring care; recognition of risk for future conditions; education and counseling of families; and health monitoring, coordination of care, and referral [22].

Primary care providers may provide much of the care for genetic disorders, in conjunction with a variety of subspecialists. However, the primary care provider may not be prepared to interpret genetic information on even the 'well understood' and relatively common genetic disorders, such as the hemoglobinopathies [23]. Thus, the geneticist becomes 1 of several providers involved in provision of care. In addition to medical providers, state programs such as those for children with special healthcare needs may coordinate some services. Despite involve-

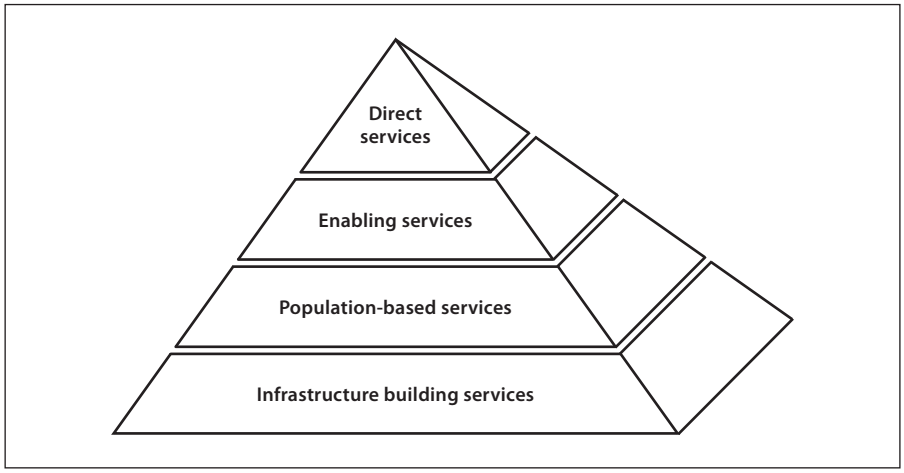

Fig. 1. Maternal and Child Health pyramid showing essential public health system components.

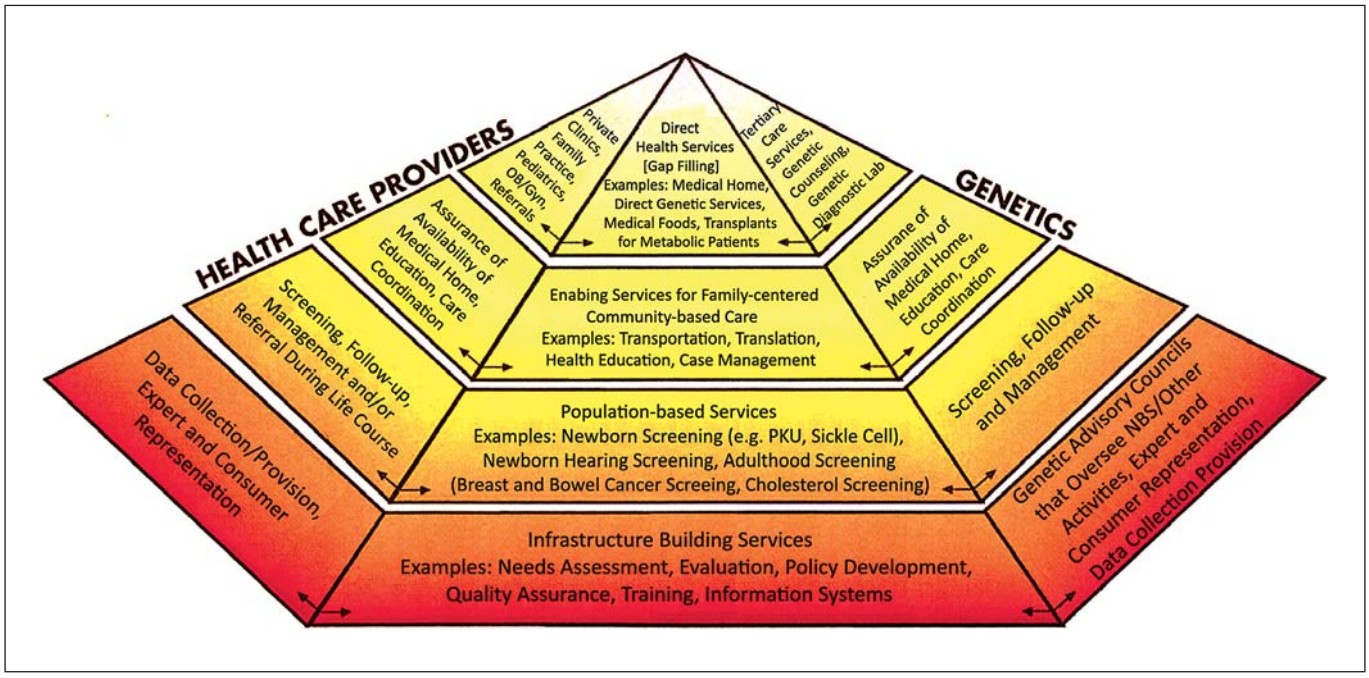

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Fig. 2. Pyramid demonstrating roles of health care providers and genetic service providers in provision of essential public health services (modified from Kaye et al. [7] with permission).

ment of many individual providers, there is often no orchestra leader for this complex combination of players. The family may serve as the repository of medical records as well as the coordinator of care. This 'model', although informal, is a mechanism for provision of genetic services as well as on-going care of a chronic condition for many individuals. However, there is generally little connection to the public health system.

Medical Home with Co-Management

The medical home concept developed among pediatricians in the 1970's [24]. The American Academy of Pediatrics defined medical home services as those that are accessible, continuous, comprehensive, family-centered, coordinated, and compassionate [24]. This model, which has gained acceptance for adult care as well, involves a

multidisciplinary team providing coordination of care based on planned visits and follow-up contacts for monitoring, delivering preventive services, and helping patients and family members in disease management [25].

Unlike the situation of the primary care provider working with other providers 'as needed', this model involves explicit or implicit co-management agreements with other providers, with coordination provided by the medical home provider and his/her team. Care is comprehensive, involving both medical and nonmedical providers. The public health system can assist the medical home provider in care coordination, development of information systems, development of screening programs, and provision of transportation and other enabling services.

To make this model work, team members within the medical home must have a clear understanding of their explicit roles as well as the roles of other providers and the public health system. They must be ready to take on these responsibilities, and they require communication tools to be effective. The geneticist may play one of several roles, from co-manager to consultant.

Emphasizing the central importance of a team-based medical home, and requiring significant time with the patient, this model has economic disincentives in practices where relatively little provider time is allocated to each patient. Primary care providers, whose numbers are not keeping pace with the increasing size and age of the population [26], represent a shrinking workforce that is sometimes inadequately trained to fulfill medical home functions, particularly in a team-based environment.

Disorder-Specific Treatment Centers

Another approach to the delivery of genetic services relies on the disorder-specific treatment center. These are comprehensive, multidisciplinary centers caring for individuals with a specific disorder or group of disorders that involve multiple organ systems. Genetic counseling services are often provided as a component of comprehensive care. These centers usually provide regular visits that emphasize surveillance for disorder complications as well as specialized care, care coordination and psychosocial support [25]. They generally do not provide primary care services, but rather work closely with the primary care provider to deliver all services required by the patient and family. Since medical home primary care providers and comprehensive disorder-specific treatment centers both strive to provide comprehensive and coordinated care, co-management plans are needed when a single individual is cared for in both systems. Disorder-specific treatment centers may interact closely with the public health system for development of policies and provision of follow-up for screening programs, and for development and maintenance of registries.

Cystic fibrosis (CF) is a genetic disorder for which care is delivered in the model of a disorder-specific treatment center in the US and Europe [27, 28]. The Cystic Fibrosis Foundation maintains a national registry of individuals with the disorder (http://www.cff.org/LivingWithCF/CareCenterNetwork/PatientRegistry/), with data contributed by center staff. Data from the registry can be used to compare outcomes of various forms of treatment as well as frequency of visits and hospitalizations [29]. With the advent of newborn screening, genetic counseling services for families with CF now occur early in the clinical course of the affected infant. Early evidence from Victoria, Australia, where newborn screening for CF was introduced in 1989, suggests that genetic counseling following diagnosis of CF by newborn screening has resulted in a declining prevalence of the disorder by 17% [30].

Individuals with hemophilia similarly generally receive care through multidisciplinary centers that provide medical and psychosocial support. A US network of these centers was begun in the 1970s, and currently more than 140 Hemophilia Treatment Centers receive federal funding to provide comprehensive care and preventive services [31]. Core team members include a medical director, a coordinator, a psychosocial professional, and a physical therapist. Additional team members include dentists, orthopedists and genetic counselors [25]. The focus of genetic counseling in families with hemophilia has been on the woman who is an obligate or possible carrier of the mutation [32]. Within the Great Ormond Street Hospital for Children NHS Trust, Haemophilia Centre, boys with hemophilia demonstrated a good awareness of genetic risks associated with their disorder. Surveys suggested that knowledge was gained from family members as well as center providers [33]. Thus, genetic counseling through a disorder-specific treatment center can be effective in providing practical genetic information to affected individuals.

Patients with inborn errors of metabolism and their families also require comprehensive clinical care, including management of acute illness that may be life-threatening. Multidisciplinary pediatric metabolic treatment centers provide care to an increasing number of these children, following the introduction of expanded newborn screening over the past decade. These centers typi-

cally combine the skills of metabolic geneticists, pediatric dieticians, social workers, nurses, and genetic counselors. Many disorders require very frequent laboratory evaluation, clinical assessment and dietary adjustment during infancy, necessitating follow-up as often as weekly. In centers where genetic counselors are part of the regular care team, families thus have the opportunity to receive counseling shortly after diagnosis of the affected child, with frequent opportunities to ask questions and receive additional information. Because treatment continues into adolescence and adulthood, formal genetic counseling can be provided to the adolescent or young adult patient [34].

Establishment of disorder-specific treatment centers in the examples cited represent major commitments by either a private foundation, the federal or state government, or an academic health center. Establishment of these centers represents high cost, as does maintenance of such a treatment center network. In addition, although multidisciplinary team development and training is receiving increased emphasis in medical education [35], current providers have received little training in these skills [36]. Also, although provision of genetic services in such centers seems reasonable, there may be no explicit linkage to genetic services. Finally, many complex genetic disorders currently lack a disorder-specific treatment center network, including diabetes, hearing loss and cancer.

Network of Genetics Clinics Linked to Medical Homes

Genetics clinics, staffed by clinical geneticists and genetic counselors, generally see a broad range of patients with a variety of genetic disorders or risk factors. Thus, providers in these centers are generalists within the broad field of clinical genetics. Such clinics now exist in most major metropolitan areas, frequently associated with academic health centers. However, there are large sections of the US with no such clinics; these regions are often served by satellite clinics of urban centers, or not at all. Telegenetics is beginning to offer an alternative model by which genetics clinics in urban centers can offer genetic consultation and genetic counseling to rural and outreach areas [37, 38].

At present, there is no organized network of such genetics centers. Individuals seeking genetic services generally rely on other providers for referrals to existing centers or on internet resources to identify possible providers. A network of regional genetics and newborn screening collaborative centers, established by the Health Resources and Services Administration in 2004 (http://www.nccrcg.org//Am/Template.cfm?Section=Home5) is one mechanism by which individuals seeking genetic services throughout the US can identify an appropriate center.

Development of an organized network of such centers can be envisioned on a regional basis. Such a network might depend on a backbone of children's hospitals, federally qualified health centers, integrated health plans, health science centers, state public health services, or a combination of these. The essential feature would be the location of such centers throughout the US, with all regions having access to a group of qualified providers. Individual patients would access services at the central location, through satellite clinics or through telemedicine services. The public health system could provide needs assessments, population screening, transportation and other enabling services, and even direct services in some instances.

Clearly, barriers exist to the creation of such a network. A dispersed network of highly specialized services depends on the existence of effective medical homes, to ensure coordination of care and access to local resources. Thus, a national network of genetics clinics requires national availability of medical homes. The relatively small number of practices that are fully functional medical homes is a barrier, as is the small number of genetics providers. The previously cited lack of training of effective teams is another factor. In geographic areas with dispersed populations, one center may serve more than a single state, requiring relationships with more than one public system as well as mechanisms for provision of services across state lines. Current reimbursement for genetic services remains a problem as well, since such services take long hours of provider time, much of which is not reimbursed in the current model.

Tools to Support Genetic Practice Models

Whatever the model for provision of genetic services, certain tools should be available to assist the providers in reaching the wide range of patients requiring help. These include facilities for outreach clinics, telemedicine facilities and other distance strategies that are readily available and economically accessible to busy clinicians, and information technology including electronic health records, just-in-time management plans and emergency management tools. The public health system can play a role in provision of these tools.

Learning Which Care Is Best

Tools have been developed to assist clinicians and the public to determine if genetic services currently being provided are of high quality. One example of such a toolkit is available for newborn screening. A model performance evaluation and assessment scheme has been developed to identify quality indicators for self-assessment of the only population based genetic screening offered in the US [39].

Other assessment tools have been developed to determine how patients and families rate the quality of genetic services they receive [40–42]. However, the array of available quality assessment tools is limited. To develop quality improvement tools for service delivery, gaps in the availability of specific tools need to be identified, metrics for quality assessment need to be developed, and a measurement system including process and outcomes must be outlined. Once such a system is available, it must be piloted, evaluated, improved, and then implemented broadly. In an era when quality and safety have become national priorities [43], it is time for genetics to join the parade.

Numerous projects have been initiated to begin to close the quality assessment gap. These include long-term follow-up of newborn screening projects funded by the Health Resources and Services Administration in several states (N.Y., Colo., Utah, Ind.) (http://mchb.hrsa.gov/programs/newbornscreening/index.html), the Centers for Disease Control long-term follow-up projects (Calif., Utah, Iowa, N.Y.) (http://www.cdc.gov/ncbddd/pediatricgenetics/key_findings.html) and the work of the Newborn Screening Translational Research Network, funded by the National Institute of Child Health and Human Development (http://www.nbstrn.org). All will provide data, at least in the realm of newborn screening, that will inform future decisions on quality improvement for genetic services. Similarly, regional networks are being formed to coordinate care for individuals with sickle cell disease and to align with the Sickle Cell Disease and Treatment Program of 2004. A major component of these programs will be quality assessment and quality improvement. The hemophilia and cystic fibrosis treatment centers discussed previously also have quality assessment and improvement programs.

Several factors would improve the functioning of any quality assessment and improvement system. These include the availability of uniform disease definitions and diagnostic criteria, so that outcomes research could focus on well-defined conditions. Data elements to be followed need to be defined carefully, and long-term support for longitudinal data collection using a single information infrastructure is required. The public health system has a role in development, dissemination, and use of these definitions, diagnostic criteria, and data elements. Availability of a network of providers caring for the same condition and linked to the medical home would also be an asset. This would permit investigators to study outcomes that involve the full range of human functioning. Once data collection tools and data collection are in place, regular data mining and analysis are needed to establish best practices.

The adoption of electronic health records by an increasing number of providers represents an opportunity for both data collection and integration. Connection of these patient records to public health data systems represents an opportunity for population surveillance and identification of best treatment practices for large populations. Systems are under development to allow diverse records to be combined, holding the promise that databases can be created with information from public as well as private sources. This is an unprecedented opportunity to collect and analyze data quickly and improve care in shorter and shorter periods of time. As this new technologic opportunity becomes increasingly available, it is important to remember that there remain providers and patients who do not have access or do not prefer to use electronic records, including some providers in rural areas and some who care for migrant and first American populations. Efforts must be made to include these populations in all studies so that outcomes can be improved for all populations.

Quality improvement and translational research share a common language when information technology is discussed. Disorder registries are a powerful tool for both, but to be effective, there needs to be agreement on definitions, data elements, informed consent, and clarification of the relationship of follow-up information to public health databases (vital records, immunizations, prenatal screening). The public health system has created large and valuable databases; newborn screening and birth defects registries are just 2 examples. However, more are needed and possible, including continuous childhood screening for hearing loss, developmental disorders and chronic disease risk factors; and adult screening for breast cancer, diabetes and heart disease risk factors. Longitudinal information is the key to improving outcomes.

Genetic Workforce

Whatever the service delivery model, someone needs to actually do the work. Much has been written [44] about the small and shrinking number of clinical geneticists in the post-human genome era. To address the shortage, it would be good to understand it. Why are so few young physicians choosing clinical genetics as a career? Is it not interesting? Too difficult? Too academic? Too hard to make a living? An understanding of the factors that underlie the shortage would help in the development of strategies to solve it. Of those who are finishing training, we need to be sure that they have skills in working with interdisciplinary teams, and they need to be willing and able to co-manage patients with medical home providers.

Assuming that the number of clinical geneticists will not increase dramatically in the near future, efforts need to focus on the production of genetic counselors and other highly trained genetics providers who can fill the gap. Similarly, partnerships between primary care providers and geneticists require that primary care providers become educated and have strategies for applying new knowledge in a rapidly evolving field [45]. One model involves the use of genetic counselors within primary care practices [46].

Conclusion

The knowledge explosion in genetics and the revolution in technology are two factors that are changing the face of genetic service delivery. There is reason for optimism. We have promising models for service delivery, quality improvement tools and emerging evidence on best practices. This is enough for a strong start toward delivery of genetic services to all of the population, to improve the health of each individual and of all.

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