

Genetic Services Plan for Wisconsin

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Abstract

During 1999-2001, a multidisciplinary group met to develop a plan for the future of genetic services in Wisconsin. The result was *The Genetic Services Plan for Wisconsin* (available at www.slh.wisc.edu/genetics/stateplan_toc.html), a problem-oriented needs-identification guide to address current and future challenges likely to affect the provision of genetic services in Wisconsin. The Plan is directed to all individuals who have a stake in the future of medical genetic services in Wisconsin. These include, but are not limited to, primary and other health care professionals, genetics professionals, governmental representatives, policy makers, legislators, educators, third-party payers, and current and potential consumers. This article provides an overview of *The Genetic Services Plan for Wisconsin* (Plan) and highlights the recommendations made for the continuing integration of new genetic knowledge across the con-

tinuum of medical care delivery in Wisconsin.

Introduction

Genetics can mean many things. In medicine, genetics can refer to changes in genes, including disorders that are passed on in families; birth defects and their causes; and complex multifactorial conditions where genetic and non-genetic factors play a role in the development of a disorder, such as diabetes, heart disease, and cancer.

Medical genetics is a relatively young specialty, which deals with all of these issues and their impact on individuals and families. Although its roots reach back over millennia, genetic services have been a part of clinical medicine for only the past few decades. In the past, clinical genetics professionals primarily addressed issues related to birth defects and rare genetic disorders—conditions that affect approximately 3%-4% of the population. Although problems related to access, service delivery, and funding existed, most problems seemed manageable given the limited scope of services provided.

Today a new face of genetics is emerging. The rapid advances in genetics due to the Human Genome Project and other scientific endeavors create challenges far greater than those faced in the past. Genetics has effects across the lifespan, and genetic principles cut through every medical subspecialty. Advances in

molecular diagnosis and treatment are challenging health care providers and the public ethically and morally.

Benefits of Genetic Care

Genetics professionals aid family members in understanding a diagnosis and its implications; this allows for informed decision-making regarding health care as well as reproductive decisions. The nondirective manner of genetic care seeks to assure that the decisions families make will be fully informed and ultimately their own. In addition, genetics professionals can offer families anticipatory guidance.

Specific diagnosis is the cornerstone of preventive care in genetic disorders. When a diagnosis is established, whether by testing or clinical assessment, the affected individual or family can be educated regarding the prevention of future medical problems and the identification of risk in other family members. Presymptomatic genetic diagnosis and predictive testing for predisposition to disorders such as cancer and heart disease can provide an opportunity for anticipatory guidance and risk reduction that not only will help the affected individual and family, but also can reduce overall health care costs.

Why a Statewide Genetic Plan?

Until now, planning has been limited as to how best to provide these and other genetic services in Wisconsin.

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However, this type of planning is especially needed given the current explosion in genetics information and technology. *The Genetic Services Plan for Wisconsin* is one step in the process of planning for the future provision of genetic services for the people of Wisconsin.

Current Structure and Services

During the past four decades, a complex, multifaceted set of genetics programs has arisen in Wisconsin. These include direct clinical care services, as well as activities ranging from screening programs and laboratory services to educational activities and birth defects surveillance.¹ Historically, service provision in genetics was primarily through University-based centers. Currently, Wisconsin has both public sector and private genetics service providers.

Assessment of Current Programs in Medical Genetics in Wisconsin

An essential component of the creation of the Plan was an assessment of the current status of genetic services in public health in Wisconsin. As a first step, the Council of Regional Networks for Genetic guidelines (<http://genes-r-us.uthscsa.edu/resources/pdf/geneticguidelns.pdf>) were compared with current structure and services in Wisconsin, and strengths and weaknesses were identified. Based on that comparison, the following strengths were identifiable:

- Presence of a genetics professional within the state system. A genetic counselor currently serves as Wisconsin's State Genetic Coordinator. This position is located in the Division of Public Health, Bureau of Community Health Promotion.
- Existence of a well-established, well-respected and effective

newborn screening program. It is estimated that 99% of all Wisconsin newborns receive newborn screening.

- Existence of active and highly successful outreach programs for care, in addition to genetic services available in Green Bay, La Crosse, Madison, Marshfield, and Milwaukee.
- Emphasis on educational efforts in a variety of formats and for a variety of audiences. These efforts include a post-doctoral training program, a genetic counselor training program, extensive CME activity, teacher-educator programs, and programs for schools, for the public, and for a variety of support organizations.
- Emphasis on ongoing management and comprehensive care of conditions traditionally viewed as genetic. Comprehensive care and specialty clinics are available for conditions such as sickle cell anemia and associated disorders, skeletal dysplasias, neurofibromatosis, cystic fibrosis, and genetic vision and hearing loss.
- Presence of special expertise regarding the care of individuals with specific groups of genetic disorders; for example, biochemical genetics clinics are located in Madison and Milwaukee; craniofacial disorders clinics are in Madison, Milwaukee, and La Crosse; cancer risk counseling is available in Madison, Milwaukee, La Crosse, Marshfield, and Green Bay.

Weaknesses identified by the assessment were the underpinnings for the recommendations set forth in the Plan. These recommendations are not intended to be specific solutions. Instead, they are to be viewed as guidelines for directions and approaches to finding solutions to the numerous issues that face genetic services in the future.

Recommendations

The recommendations of the workgroup on development of a genetic services plan for Wisconsin are organized into nine primary clusters:

1. *Advisory Council.* An Advisory Council for Genetic Services should be established and modeled after the Newborn Screening Advisory Group and Council on Birth Defects Prevention and Surveillance. This Advisory Council should be charged with continuing the assessment of the status of genetics and providing guidance regarding Plan recommendations.
2. *State Presence.* Genetics in public health needs to be a program with more than one position at the state level. This program should be charged with coordinating and monitoring all genetic services in the state, overseeing the transition of emphasis to include adult disorders and disease predisposition, and providing liaison to public health groups.
3. *Service Issues—Assessment and Quality Assurance.* The Advisory Council should devise means of assessing current genetic services and providing measures for quality assurance.
4. *Service Issues—Insufficient Genetics Workforce.* The Advisory Council should generate a needs assessment methodology and provide recommendations regarding workforce needs in genetics in Wisconsin.
5. *Service Issues—Financing Genetic Services.* Options for additional funding must be explored. Without additional funding, access to genetic services will be limited, and the ability of genetic providers to respond to the explosion of new information and new options will be severely hampered.
6. *Service Issues—Access.* Access

- to appropriate, comprehensive, and longitudinal care, regardless of health insurance, needs to be assured.
7. *Collaboration.* Steps should be taken to improve collaboration among genetic professionals as well as between genetic professionals and others (eg non-genetic health care professionals, managed care organizations, families, support groups, and advocacy organizations).
 8. *Issues Related to the New Genetics.* New genetic information and discoveries will likely change the face of genetic services, as well as fundamentally change the practice of medicine in general. For genetics, most pressing issues will be related to adequate education of primary care professionals and to workforce limitations. Both of these issues will need to be addressed to adequately care for all Wisconsin families.

9. *Education-Related Issues.* Educational initiatives are fundamentally important to the future viability of genetic services. Educational efforts should be directed towards physicians, other health care professionals, administrators, governmental representatives, legislators, the general public, and those in need of direct genetic services.

Discussion

Since completion of *The Genetic Services Plan for Wisconsin* in 2002, progress toward addressing the recommendations of the Plan has been limited by resources and available staffing. In March 2004, a new multidisciplinary workgroup was brought together to further prioritize recommendations made in the Plan. Priorities identified at that meeting served as the basis for the formation of four distinct subcommittees: Finance and Public Policy; Education; Workforce; and Access

and Outcomes. Each subcommittee was charged with organizing its membership to develop a workplan with preliminary goals, action steps, and timelines addressing its respective focus area.

Although state resources to support these efforts remain limited, stakeholders with a vested interest in the future of medical genetics services in Wisconsin continue to be dedicated to the cause. In addition, unexpected opportunities to benefit from a federally funded regional collaborative of states to address issues of genetic service provision have buoyed confidence that progress will continue with relation to implementation of the recommendations in *The Genetic Services Plan for Wisconsin*.

References

1. Oftedahl E, Pauli RM, Fleischfresser S, Katcher ML. Wisconsin Birth Defects Registry collecting data. *WMJ.* 2004;103(5):19-21.

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