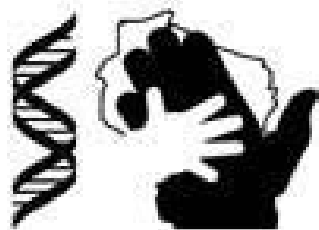


**The Here and Now of Genetics in Wisconsin:
Results from the Wisconsin Genetics System
Needs Assessment Surveys**

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Introduction

The Wisconsin Genetics System is a network of public health and clinical providers which strives to promote and improve the status of genetic services in Wisconsin. The System derives its mission from the Genetic Services Plan for Wisconsin and is primarily funded by monies from the Maternal and Child Health Services Title V Block Grant. The Wisconsin Department of Health and Family Services (DHFS) acts as the administrator of grant funds, which are currently awarded as a contract to Children's Hospital of Wisconsin (CHW) on the contingent that sub-contracts are subsequently given to Marshfield Clinic Genetics and the University of Wisconsin-Madison Clinical Genetics Center.

As part of its 2006 and 2007 contracts, CHW was required to conduct a needs assessment of existing genetic services in Wisconsin. It was determined a comprehensive needs assessment would need to include two components: a measure of the awareness of and referral to genetic services by non-genetic medical providers, and a definition of current service delivery capacities of clinical genetics providers. CHW investigators addressed the former issue, while DHFS undertook the task of achieving the latter.

Survey Methods

Non-Genetic Medical Providers Survey

The original survey distributed by CHW was adapted from the Iowa Needs Assessment and the Wheaton Franciscan Services, Inc. assessment. The survey was created via and posted on surveymonkey.com. The survey was designed to target physicians practicing in certain specialties. Most questions were intended to be answered by all those surveyed, but certain subsets of questions were asked only of those who self-identified as practicing a designated specialty.

In October 2006, a letter explaining the purpose of the survey and requesting its online completion was sent to 4,828 physicians throughout the state of Wisconsin in the specialty areas of Family Practice, Internal Medicine, Obstetrics and Gynecology, Pediatrics, Hematology/Oncology, and Oncology. Physician names and contact information were obtained from a Children's Hospital of Wisconsin internal database of all physicians in Wisconsin, northern Illinois, and areas of upper Michigan. The database is updated quarterly using data from American Medical Information. The letter to physicians was sent on CHW letterhead and in CHW envelopes. The survey was made accessible through a link on a CHW website. After a two-month period, the survey response rate was approximately 1%.

This low response rate prompted revision of the survey. Attempts were made to obtain needs assessment surveys used previously in Colorado and Texas as part of their State Genetics Plans, but the attempts were unsuccessful. Once CHW staff completed the revision process, the final result was a 42-item questionnaire divided into five general sections: Background, External Genetics Services, Genetics in Your Practice, Perspective, and Genetics Education.

The survey was resent in August 2007 to 6,380 physicians throughout the state in the specialty areas of Family Practice, Internal Medicine, OB/GYN, Pediatrics, Hematology/Oncology, and Oncology. Letters explaining the purpose of the survey and requesting its online completion were again sent, but this time they were sent on State of Wisconsin letterhead and in State envelopes. On several occasions, individuals suggested the low response rate could be due, in part, to a perception on the part of physicians that the survey was an internal CHW project rather

than part of a statewide initiative. The survey was again created via and posted on surveymonkey.com, but a link to the survey was made accessible through a State website. Responses were collected through October 2007.

Clinical Genetics Providers Survey

After examining a number of states' needs assessment surveys, investigators at DHFS adapted the "Illinois Statewide Genetics Needs Assessment Survey for Clinical Genetics Service Providers" for use in Wisconsin. The final result was a 36-item questionnaire divided into six general sections: Provider Information, Professional Time Allocation, Clinical Patient Care, Clinical Service Capacities, Clinical Outreach Services, and Genetics in Wisconsin. Four additional questions addressing provider background (gender, age, race, ethnicity) were included at the end of the survey and answering was optional.

The Statewide Genetics Coordinator at DHFS has access to a list of all medical geneticists and genetic counselors in Wisconsin. At the time the survey was initiated, there were 15 medical geneticists and 47 genetic counselors active in the state, for a total of 62 genetics providers. In December, 2006, an unmarked, non-coded survey was sent to each provider, accompanied by a cover letter explaining the purpose and intent of the questionnaire. Once a provider had completed a questionnaire, it was returned to DHFS in a self-addressed, postage-paid envelope with no indication as to the sender. As a result, all responses were anonymous.

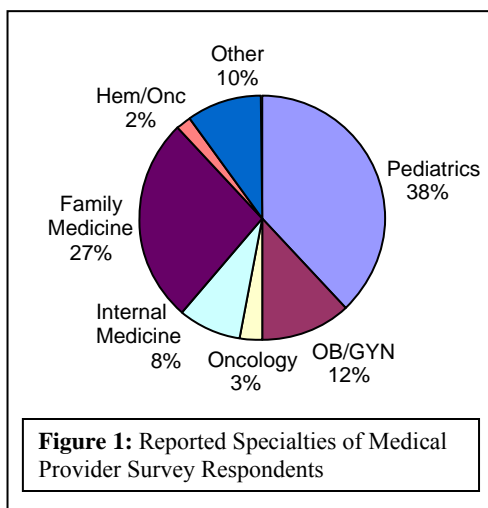
In January, 2007, a follow-up letter was sent out to all genetics providers, thanking those who had returned a questionnaire and encouraging all those who had not yet done so to complete the survey. In February, an email was sent to those for whom an email address was available with the survey as an attachment and a final request to complete the survey. Data collection was completed in March. Answers were entered into Microsoft Excel spreadsheets and all calculations and analysis of the results were performed using Excel.

Results: Non-Genetic Medical Provider Survey

A total of 5,929 survey invitations were successfully delivered to non-genetic medical providers (from this point forward referred to as "medical providers"). Of those, 122 (2.06%) completed the survey as available on surveymonkey.com.

Provider Background

The majority of respondents identified themselves as specializing in pediatrics (38%) or family medicine (27%). Approximately 10% of medical providers self-identified as being in the "other" category, specifying infectious disease, radiation oncology, nurse midwifery, or described themselves as retired (Fig. 1). Any respondents who identified themselves as belonging in the "other" category were not asked specialty-specific questions throughout the survey.



Based on zip codes provided in answer to a survey question, respondents are distributed across the state as seen in Table 1. The majority of respondents are located in the Milwaukee area (Milwaukee/Waukesha counties, 39.5%) and the Madison area (Dane/Jefferson counties, 14.0%).

Table 1: Distribution of Medical Providers by County Based on Reported Zip Code

Counties	Percent Providers Reporting Zip Code in County
Milwaukee/Waukesha	39.5%
Dane/Jefferson	14.0%
Brown/Outagamie/Winnebago	9.7%
Green/Rock	7.0%
Dodge/Fond du Lac	5.3%
Calumet/Manitowoc/Sheboygan	4.4%
La Crosse/Monroe	4.4%
Adams/Portage/Wood	3.5%
Racine/Walworth	3.5%
Eau Claire	2.6%
Columbia/Sauk	1.7%
Pierce/Polk	1.7%
Door	0.9%
Richland County	0.9%
Vilas	0.9%

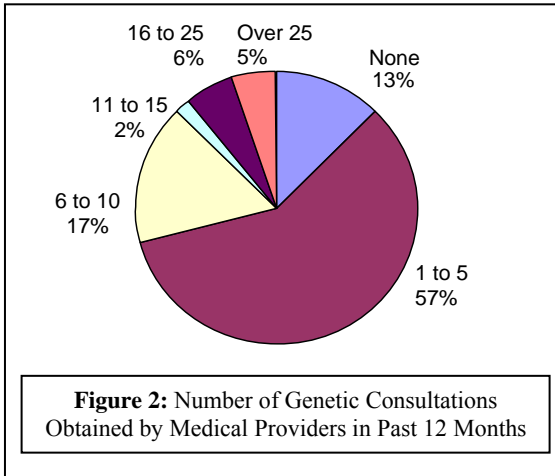
Genetics in Practice/External Genetic Services

Medical providers were asked several questions about their utilization of genetic concepts and genetic specialty services in their regular practice. Several questions focused on their use of the family history as a screening tool. The vast majority (96.7%) of responding physicians routinely take a family history. Of those who do take a family history, the vast majority (93%) take it early in the care of a patient on a routine basis, while 37.7% take a family history to assess a specific problem in the patient as needed. The majority (89.4%) of family histories taken by the physicians include medical risk factors (e.g. hypercholesterolemia, cancer, heart attack, stroke). 48.7% of family histories taken by reporting physicians include completion of a standard form or checklist, 46.0% include two or three generations in the family history, and 36.3% include the family’s ethnic background.

At some point, medical providers may need to refer a patient for genetic counseling or consultation. Of those providers responding to the survey, 88% have referred a patient to another facility or physician/physician group for genetic counseling or consultation, and the majority utilizes a medical geneticist (70.9%) and/or a genetics nurse/counselor (62.1%) for counseling or consultation. Of those who have referred a patient for genetic counseling or consultation, 56.3% utilized services located in the Milwaukee area, 30.1% in Madison, 9.7% in Marshfield, 6.8% in La Crosse, and 4.9% in the Chicago Metropolitan area. 16.5% reported utilizing services in “other” locations, including Green Bay, Neenah, Racine, and Rhinelander in Wisconsin, as well as out of state services in Minnesota and California. It can be assumed most of the “other” locations reported in Wisconsin are outreach clinics staffed by the major genetics centers in the state.

Genetic consultation and counseling are periodically available to underserved populations through outreach clinics. 83.5% of medical providers were not aware of genetics outreach services that visit their area regularly. Of the 16.5% of medical providers who were aware of

outreach services, a variety of outreach locations were reported, including Rhinelander and Racine.



103 medical providers responded to a question inquiring how many genetics consultations they obtained in the last 12 months. A majority of providers (87%) obtained at least one genetics consultation in the past year, with most (57%) making 1 to 5 referrals. A small percentage (5%) obtained over 25 consultations over the course of one year (Fig.2).

Reasons for referral to genetics are variable. As part of the survey, medical providers of each specialty were given a list of symptoms relevant to their specialty and asked to rank how often they refer patients with each symptom for genetics consultation. Choices

for frequency of referral were “Usually”, “Sometimes”, and “Rarely”. Table 2 indicates for each specialty the three most common indications the majority of medical providers in that specialty “usually” refer for genetics consultation and the three most common indications “rarely” referred for genetics consultation by a majority of providers in that specialty.

Table 2: Indications for Referral to Genetics by Specialty According to Medical Provider Report

	Pediatrics/Family Medicine		Internal Medicine/Family Medicine		OB/GYN		Hematology/Oncology	
	Indication	%	Indication	%	Indication	%	Indication	%
<i>Usually Refer</i>	Metabolic Disorders	76.4	Family History of Huntington Disease	60.6	Family History Genetic Disorder	80.6	Family/personal History of Breast Cancer	34.8
	Birth Defects	59.5	Family/personal History of Cancer	55.6	Abnormal Fetal Chromosomes	71.9	Family/personal History of Ovarian Cancer	34.8
	Dysmorphic Features	57.3	Birth Defects or Dysmorphic Features	54.5	Abnormal Screening Test	71.9	Family/personal History of Thyroid Cancer	28.6
<i>Rarely Refer</i>	Behavior Problems	78.8	Osteoporosis	93.8	Infertility	56.7	Family/personal History of Prostate Cancer	95.2
	Overgrowth Stature	66.2	Familial Hypercholesterolemia	87.5	Ethnic-related disorders	43.3	Family/personal History of Kidney Cancer	71.4
	Fetal Exposure to Teratogens	58.0	Alzheimer disease or Parkinson disease	84.8	Family History Mental Retardation	32.3	Family/personal History of Thyroid Cancer	61.9

Pediatricians were most likely to refer patients with metabolic disorders, and least likely to refer patients with a fetal history of teratogen exposure. Internists were most likely to refer a patient with a family history of Huntington disease, and least likely to refer a patient with Alzheimer or

Parkinson disease. OB/GYN's were most likely to refer patients with a family history of a genetic disorder, and least likely to refer patients with a family history of mental retardation. Hematologists/oncologists were most likely to refer a patient with a family and/or personal history of breast cancer, and least likely to refer a patient with a family and/or personal history of thyroid cancer (although 28.6% of medical providers indicated they "usually" refer a patient with a family or personal history of thyroid cancer).

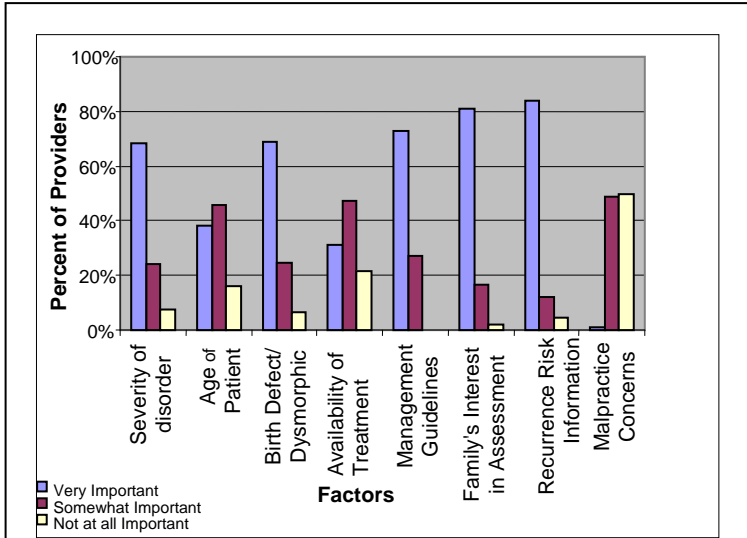


Figure 3: Importance of Factors Contributing to Medical Providers' Decision to Refer to Genetics

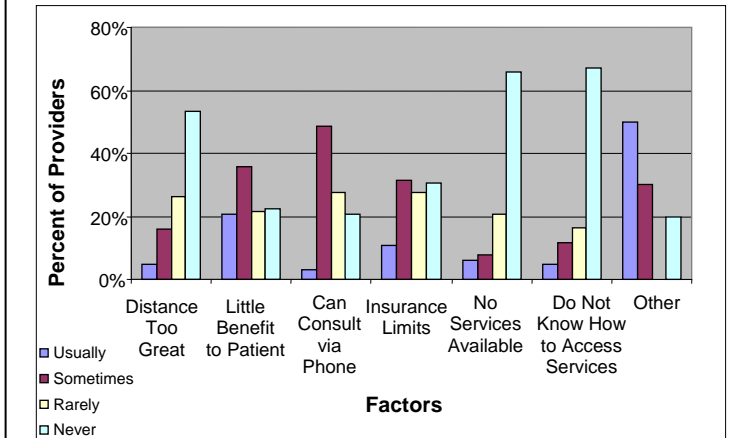


Figure 4: Frequency of Factors Used in Determining Medical Providers' Decision to Not Refer to Genetics

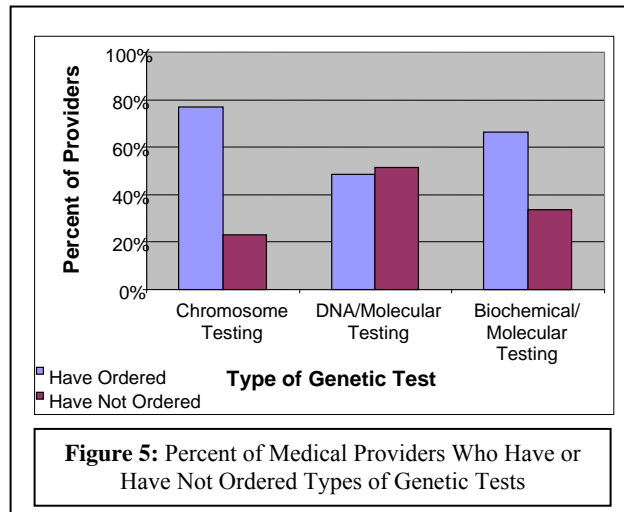
Along with the medical indication for referral, providers take into account other factors when deciding whether or not to refer a patient for genetic counseling or consultation. Medical providers were given a list of factors and asked to rank their importance in the decision to refer. The severity of the disorder, presence of birth defects or dysmorphic features, a need for management guidelines, the family's interest in assessment, and recurrence risk were all listed by a majority of medical providers as being very important, with recurrence risk listed by nearly 84% of survey respondents (Fig. 3). Providers were also given a list of factors and asked to gauge how often those factors determined when NOT to refer to genetics. A majority of providers answered that the distance being too great, no services are available, and not knowing how to access services are never factors considered when deciding to not refer to genetics (Fig. 4). Half of the providers listed "other" factors as usually playing a role; of those providers who further explained their answer, most stated the patient was not interested or declined services, or genetic services were not needed.

Medical providers were asked to estimate the percent of patients currently in their practice who have a clinically significant genetic condition. Reports ranged from 0%-90%, with most (57.5%) responses under 10%.

A major element of most genetic consultations involves the possibility of genetic testing. Medical providers have the ability to order such tests without first obtaining a consult from a genetics professional. Most survey respondents have, at some point, ordered genetic testing, particularly chromosome testing (Fig. 5). It was nearly an even split between those who have

ordered DNA/Molecular testing and those who have not. Approximately two-thirds of respondents have ordered Biochemical/Molecular testing previously.

The majority of medical providers (57.8%) who ordered any of the testing represented in Figure 5 obtained informed consent. Nearly all (92.4%) who received abnormal results for such testing discussed the results with the patient, and the majority (83.3%) who received abnormal results referred the patient for genetic consultation or counseling.



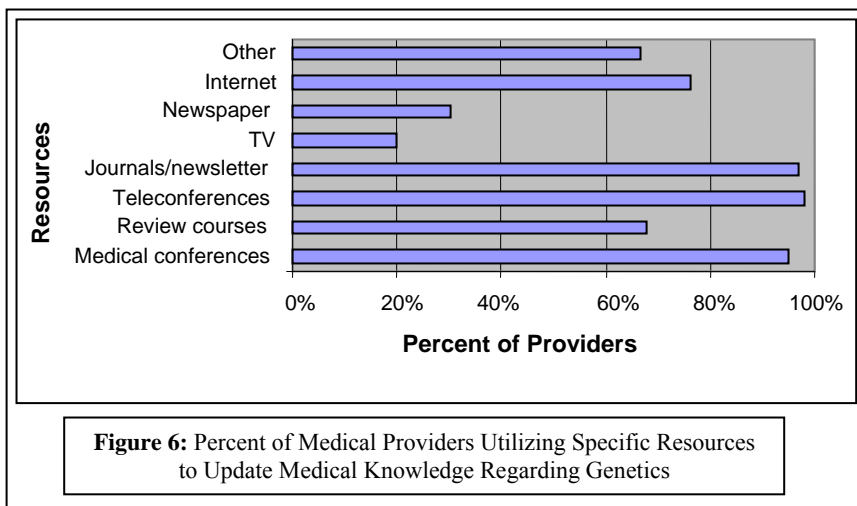
The utilization of genetic services and the practice of ordering tests may be regulated by institutional policies and procedures. However, the majority (85.7%) of medical providers claim their institutions do not have policies specifically related to genetics/genetics services.

Most (84.5%) medical providers report not having a need for genetic services beyond those presently available to them. Of those who did report having needs beyond those presently available, reason for the need fell into one of three categories

1. Unsure when or how to refer; need for education
2. Distance to nearest genetic services too far
3. Patient's health insurance restrictive in regards to genetic consultation and counseling

Genetics Education

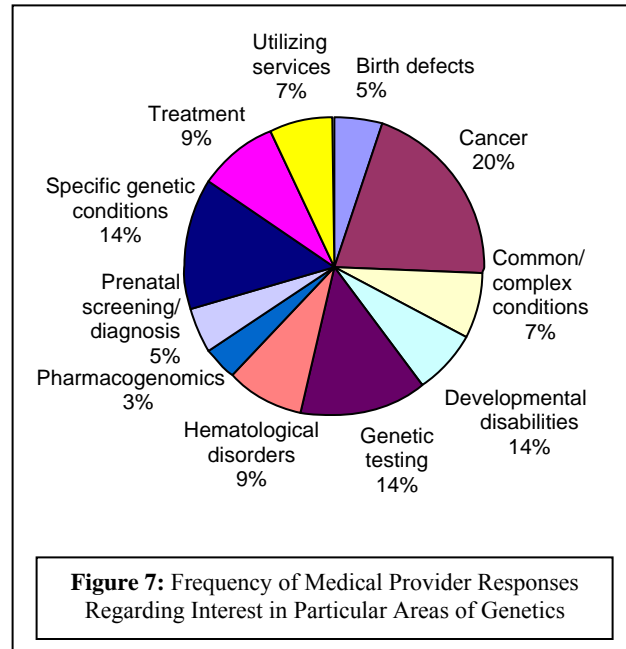
A few questions were asked regarding the education medical providers receive in the area of genetics and recent updates in genetics knowledge. Not all results to these questions are discussed in this paper, but have been made available to the Wisconsin Genetics Advisory Council Advocacy & Education workgroup for further review.



In response to a question asking about the resources used to further their knowledge about genetics in medicine, providers indicated medical conferences, satellite teleconferences, and journals or newsletters as the resources most often utilized (Fig. 6). Television and newspapers were the resources least often utilized.

Providers were also asked to indicate the areas of genetic information about which they would be most interested in learning. Certain topics were mentioned more often than others, particularly cancer (20% of responses were related to cancer) and testing for genetic conditions (14% of responses). See Figure 7. In general, responses fell into the following categories:

1. Birth defects/congenital disorders – including congenital heart disease and congenital varicella syndrome
2. Cancer – including ovarian cancer, prostate cancer markers, breast cancer screening, inheritance of cancer risk, familial cancer syndromes, counseling of patients with a BRCA mutation, and BRCA associations with non-breast cancers
3. Genetics of “common” or complex conditions – including diabetes, psychiatric disorders, and other multifactorial disorders
4. Developmental disabilities – including autism and evaluation of mental retardation
5. Genetic testing – including available up-to-date resources, new tests available and current research projects, how to initiate testing as a primary care provider, and the application of testing techniques to diagnosis
6. Hematological/bleeding disorders – including hemochromatosis and Factor V Leiden deficiency
7. Pharmacogenomics – including drug metabolism
8. Prenatal screening/diagnosis – including genetic counseling for advanced maternal age and screening for Down syndrome
9. Specific genetic conditions – including Fragile X syndrome, Huntington disease, Marfan syndrome, Turner syndrome, connective tissue disorders and metabolic disorders. Some providers also mentioned wanting a brief summary of the most common genetic conditions, including natural history information.
10. Treatment for genetic conditions – including recent therapeutic developments, stem cell treatments, and gene therapy
11. Utilizing services – including when and how to refer, cost, availability of services, and the types of patients who can benefit from a genetics consultation



Medical Provider Perspectives

Medical providers were given the option to write in their own opinions and beliefs as to the benefits of a genetics consultation. Responses fell into eight general categories as far as perceived benefits (see Table 3 for examples of provider responses):

1. Explanation of risk to other family members and for future pregnancies
2. Provision of management guidelines
3. Discussion of treatment options
4. Correct testing procedures taken, especially to confirm or rule out a diagnosis
5. Patients able to make informed decisions
6. Provision of natural history information
7. Education of patients and physicians, including opportunities to ask questions
8. Provision of quality care, expert advice, and counseling

Medical providers were also given the option to write in their own opinions and beliefs as to the disadvantages of a genetics consultation. Responses fell into eight general categories (see Table 4 for examples of provider responses):

1. No perceived disadvantages
2. Risk for insurance discrimination
3. Risk for general genetic discrimination
4. Barriers of cost or lack of insurance coverage for genetic services
5. Induces anxiety or is overwhelming for patients
6. Lack of information which can be provided
7. Lack of treatment options for genetic conditions
8. Lack of understanding

Medical providers were also asked their opinion as to when the impact of genetics will become significant in their own medical practice. The majority (62.8%) believe the impact of genetics is significant now, while an additional 10.8% indicated it will be 5 years or more before genetics has real impact on their practice.

At the end of the survey, medical providers were given the option to offer additional thoughts and comments; 17 providers responded. Several providers remarked upon the need for more education and the need to stay current in their own genetic knowledge, with a few mentioning a possible role for electronic medical records in helping to monitor those patients who may benefit from genetics consultation. Others stated the belief that genetics will become the next frontier medicine. While many see this as an exciting and challenging prospect, others are concerned about the misuse of genetic information or the possibility of discrimination against those with a diagnosed condition, both before and after birth.

General Concept	Quotes from Medical Providers
Explain risks to other family members/future pregnancies	<p><i>“Understanding future reproductive health risks”</i></p> <p><i>“Family understanding: information for other family members, for future children”</i></p> <p><i>“Determine possible risk factor for descendants”</i></p>
Provides management guidelines	<p><i>“Help determine when breast cancer screening should be started in high risk patients”</i></p> <p><i>“Help with maintenance issues in genetic disorders”</i></p> <p><i>“Detailed assessment and management guidelines”</i></p>
Discussion of treatment options	<p><i>“Improved outcome for those syndromes where treatment might be available”</i></p> <p><i>“Prophylactic treatments”</i></p>
Correct testing procedures, especially in determining a diagnosis	<p><i>“Interpretation of some of the more complex genetic tests”</i></p> <p><i>“Properly counseled testing, excellent assessment of whether a patient actually needs testing”</i></p> <p><i>“Definitive diagnosis given”</i></p>
Informed decision-making for patients	<p><i>“Helps patients make informed decisions about pregnancy”</i></p> <p><i>“Better decision-making regarding pregnancies and risk of developing chronic conditions”</i></p>
Provides natural history information	<p><i>“Geneticists have more familiarity with the natural history of the disorder”</i></p> <p><i>“Accurate information about nature of disease, progression, treatment, risks to future generations”</i></p>
Patient and physician education/ answering of questions	<p><i>“Ability to answer questions and offer prognosis or risk evaluation to patients”</i></p> <p><i>“Greatest benefit is in education for the physician and the patient, in increasing understanding of the problem and its origins”</i></p> <p><i>“Increasing family knowledge about their child’s condition, whatever it is. Knowledge is power”</i></p>
Quality care from expert/ availability of counseling	<p><i>“Thorough and consistent consult that is well-documented”</i></p> <p><i>“Reassurance in many cases, putting the risk of a particular problem in perspective”</i></p> <p><i>“Improved patient care”</i></p> <p><i>“High level of ‘counseling’ for patients with complex questions”</i></p>

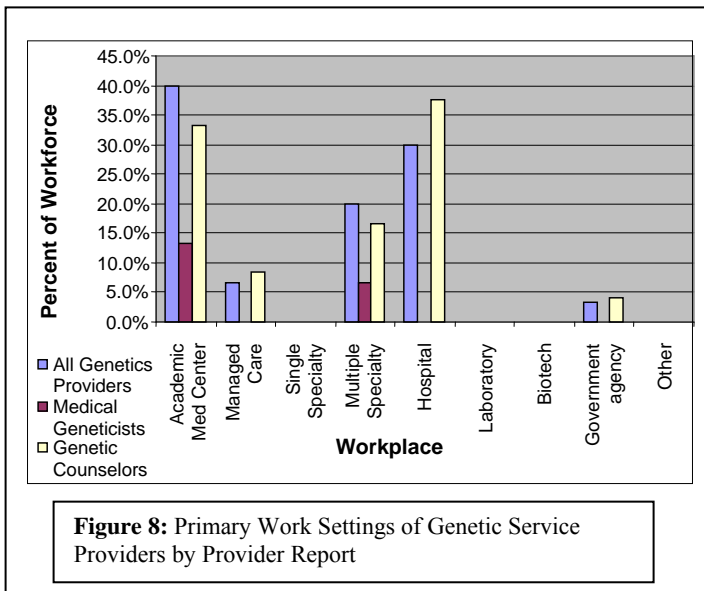
General Concept	Quotes from Medical Providers
No perceived disadvantages	<i>"None. Perhaps the 'stigma' of a genetic diagnosis but I wouldn't consider this a disadvantage."</i>
Risk for insurance discrimination	<p><i>"Potential for insurance providers to discontinue coverage of 'high risk' patients."</i></p> <p><i>"I am deeply concerned that in the future insurance companies may limit benefits to children with genetic conditions – possibly to the point of only covering the abortion if diagnosed prenatally . . . may also discriminate against persons with genetic markers for illness."</i></p> <p><i>"May be used against patients by insurance companies."</i></p>
Risk for general genetic discrimination	<p><i>"Violations of confidentiality might cause very serious problems for patients with genetic mutations that predispose to serious chronic illness."</i></p> <p><i>"Providing information that is sometimes used for bad ends (most prenatal diagnosis of Down Syndrome results in the killing of the child)."</i></p> <p><i>"The potential for genetic discrimination (ever see the movie GATTACA?)."</i></p>
Barrier of cost/lack of insurance coverage	<p><i>"Cost, especially when it is not covered by insurance – this has been a problem for BRCA counseling/testing."</i></p> <p><i>"Cost of testing"</i></p>
Anxiety-inducing/overwhelming for patients	<p><i>"Increased risk perception with no current [diagnosis of] disease can lead to emotional anxiety to the patient and family members."</i></p> <p><i>"Sometimes the family is so overwhelmed with information that they do not hear or understand some or all of it. They may be more confused than before the genetics consultation."</i></p> <p><i>"Undue guilt on the parents – it's their 'fault'."</i></p> <p><i>"Ability to cause excessive or unwarranted worry for relatively benign conditions, potential for confusion and ostracism within a family"</i></p>
Lack of information provided	<p><i>"Not always able to find an answer and then the parents often feel we are just trying to find things wrong with their child."</i></p> <p><i>"There is still too much that is unknown, thus the consultation will often be biased to the counselors' opinions."</i></p> <p><i>"Many times the answer is 'You have something, we just don't know what it is yet.' This can be frustrating for families."</i></p>
Lack of treatment options	<p><i>"Sometimes no treatment is available for the condition."</i></p> <p><i>"Diagnosing without treatment options or unethical medical treatments."</i></p> <p><i>"Potential to label a young child with a condition that is untreatable but asymptomatic until adulthood."</i></p>
Lack of understanding	<p><i>"Lack of patient understanding once results are explained. It is difficult for some patients to fully comprehend "25%" risk versus "0.1% risk."</i></p> <p><i>"Need to make sure patient truly understands what information means: all implications, possible discrimination, etc."</i></p>

Results: Clinical Genetics Provider Survey

Of the 62 genetic services providers who received a survey, 30 (48.4%) returned a completed questionnaire to DHFS. This included 6 of 15 medical geneticists (40%) and 24 of 47 genetic counselors (51%).

Demographics/Provider Information

Based on zip codes provided in answer to a survey question, respondents are distributed across the state thusly: Madison area: 43.3%, Milwaukee/Waukesha area: 26.7%, Marshfield: 13.3%, Green Bay: 10%, LaCrosse: 3.3%, Neenah: 3.3%. It is unknown if these numbers are representative of the entire genetic service provider population in Wisconsin, but they may be a fair estimate.

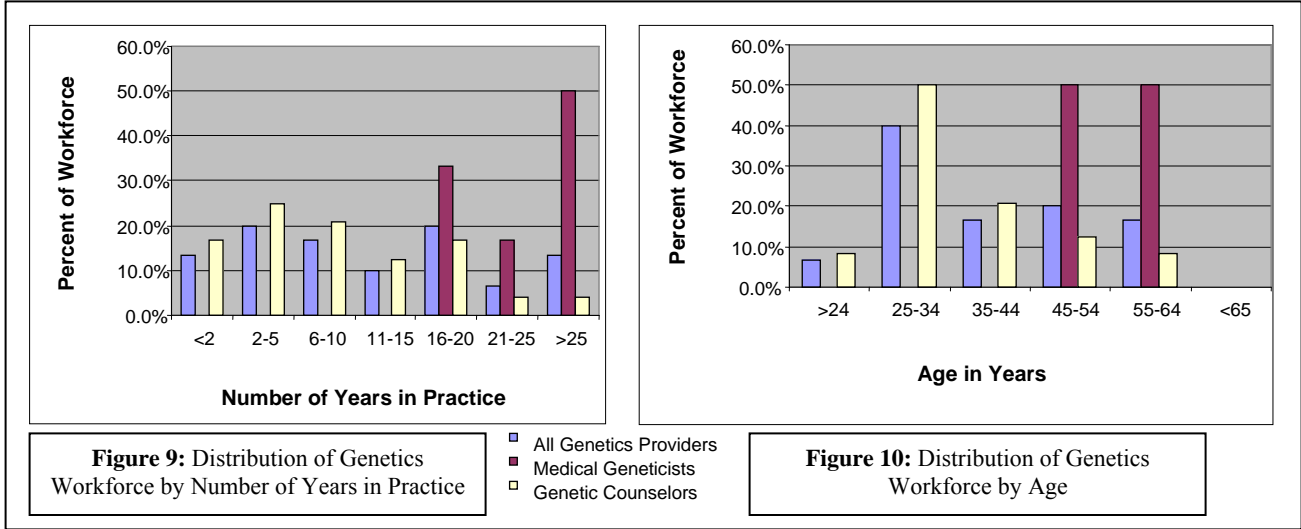


20% of genetic service providers in the state have an MD degree, and 13.3% hold a PhD (half of those with an MD also have a PhD). Approximately 83% hold an MS or MA, and 3% are registered nurses. Nearly 87% are certified in their profession (either by the American Board of Medical Genetics or the American Board of Genetic Counseling), while about 23% are eligible for certification. A majority (66%) of medical geneticists also report being certified as pediatricians, though 100% report specialty training in pediatrics. Other areas of reported specialty training include perinatal grief, public health, and population

genetics. A majority of respondents work primarily in an academic medical center or hospital, though some report working in a managed care facility, multiple specialty practice or government agency (Fig. 8). No medical geneticists report working in a hospital, while this was the setting most frequently reported by genetic counselors.

Medical geneticists and genetic counselors displayed definite differences in the number of years spent working in the field. While all medical geneticists reported working 16 or more years in the genetics profession, a majority (62%) of genetic counselors have worked fewer than 10 years (Fig. 9). Similarly, distribution according to age shows two distinctly different trends for genetic counselors versus medical geneticists: a majority of genetic counselors (58%) are under age 34, while 100% of medical geneticists are between the ages of 45 and 64 (Fig. 10).

All respondents reported their race as Caucasian and their ethnicity as non-Hispanic. 80% of providers are female, largely due to the fact that approximately 96% of responding genetic counselors are female. In addition, 17% of responding medical geneticists are female.



Time Allocation

Genetic providers in Wisconsin spend an average of 26.6 hours per week involved in genetics-related activities. This figure includes information from both full-time and part-time providers. Medical geneticists average approximately 48.3 hours per week, while genetic counselors average approximately 35.5 hours per week.

A majority of this time is spent in clinical patient care. 77% of providers report spending at least half of their workweek in patient care, including 100% of medical geneticists and 71% of genetic counselors. Other activities include clinical laboratory work, clinical research, other research, grant writing, publication writing, teaching and education, and administration (Table 5).

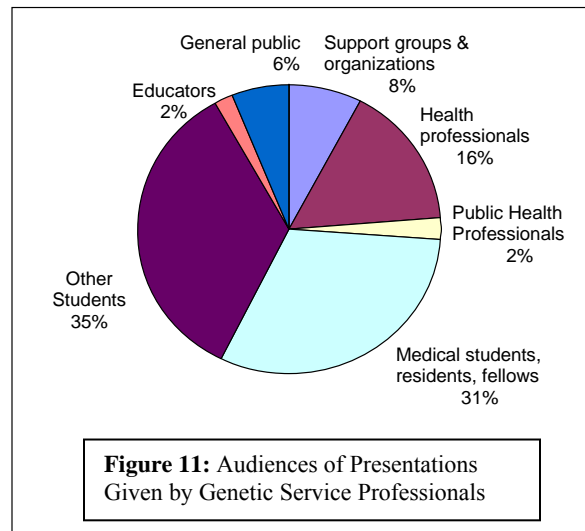
A majority of genetic service providers in Wisconsin are engaged in at least some clinical patient care during an average workweek. Patient care involves a variety of aspects and is not solely a measure of how much time a provider spends in face-to-face interactions with patients. Providers report varying amounts of clinical time actually spent in person with patients. Every medical geneticist reported spending at least more than a quarter of their time with patients, but no more than 60% in an average week. Genetic counselors reported more variety, with some spending as little as 10% of clinical time with patients, and some as much as 75% (Table 6). In general, though, providers spend more time in direct contact with patients than in any other clinical care activity.

Table 5: Percent of Time Providers Spend in an Average Workweek on Genetics-related Activities

Activity	Percent Time Spent									
	0%	1-10%	11-25%	26-40%	41-50%	51-60%	61-75%	76-90%	91-99%	100%
Clinical patient care	3.3%		10.0%	3.3%	6.7%	10.0%	23.3%	13.3%	26.7%	3.3%
Medical Geneticists						50.0%	50.0%			
Genetic Counselors	4.2%		12.5%	4.2%	8.3%		16.7%	16.7%	33.3%	4.2%
Clinical laboratory work	86.7%	3.3%	6.7%				3.3%			
Medical Geneticists	66.7%		33.3%							
Genetic Counselors	91.7%	4.2%					4.2%			
Clinical research	60.0%	23.3%	13.3%	3.3%						
Medical Geneticists	16.7%	33.3%	33.3%	16.7%						
Genetic Counselors	70.8%	20.8%	8.3%							
Other research	96.7%	3.3%								
Medical Geneticists	100.0%									
Genetic Counselors	95.8%	4.2%								
Grant writing	86.7%	10.0%	3.3%							
Medical Geneticists	83.3%	16.7%								
Genetic Counselors	87.5%	8.3%	4.2%							
Publication writing	66.7%	30.0%	3.3%							
Medical Geneticists	33.3%	66.7%								
Genetic Counselors	75.0%	20.8%	4.2%							
Teaching/ Education	20.0%	46.7%	26.7%	3.3%		3.3%				
Medical Geneticists		50.0%	33.3%	16.7%						
Genetic Counselors	25.0%	45.8%	25.0%			4.2%				
Administration	43.3%	30.0%	16.7%	3.3%		6.7%				
Medical Geneticists	33.3%	16.7%	50.0%							
Genetic Counselors	45.8%	33.3%	8.3%	4.2%		8.3%				

All providers: n=30; Medical geneticists: n=6; Genetic counselors: n=24

As indicated in Table 5, genetic service providers also spend a certain amount of time educating various audiences about genetics. A majority of educational presentations are given to students; either medical students or other students (high school, college undergraduate, or graduate). Presumably, this includes presentations to genetic counseling graduate students and medical genetics fellows, as programs for both are to be found in Wisconsin. Other educational lectures or presentations have been given to health and public health professionals, support groups & organizations, educators, and the general public (Fig. 11). A total of 442 presentations were reported as being given in 2006: 152 by medical geneticists and 290 by genetic counselors.



Activity	Percent Time Spent									
	0%	1-10%	11-25%	26-40%	41-50%	51-60%	61-75%	76-90%	91-99%	100%
Pre-clinic preparation		31.0%	58.6%	10.3%						
Medical Geneticists		50.0%	50.0%							
Genetic Counselors		26.1%	60.9%	13.0%						
Research/ review of literature	6.9%	55.2%	34.5%	3.4%						
Medical Geneticists		50.0%	50.0%							
Genetic Counselors	8.7%	56.5%	30.4%	4.3%						
Face-to-face patient interaction		13.8%	24.1%	24.1%	24.1%	10.3%	3.4%			
Medical Geneticists				33.3%	33.3%	33.3%				
Genetic Counselors		17.4%	30.4%	21.7%	21.7%	4.3%	4.3%			
Over-the-phone patient interaction		58.6%	37.9%	3.4%						
Medical Geneticists		83.3%	16.7%							
Genetic Counselors		52.2%	43.5%	4.3%						
Ordering tests		93.1%	6.9%							
Medical Geneticists		100%								
Genetic Counselors		91.3%	8.7%							
Interpretation of test results	10.3%	75.9%	13.8%							
Medical Geneticists	16.7%	83.3%								
Genetic Counselors	8.7%	73.9%	17.4%							
Insurance/ payment/ billing issues	6.9%	69.0%	24.1%							
Medical Geneticists		83.3%	16.7%							
Genetic Counselors	8.7%	65.2%	26.1%							
Writing/ dictating letters and clinic notes										
Medical Geneticists	3.4%	34.5%	41.4%	17.2%			3.4%			
Genetic Counselors	4.3%	34.8%	39.1%	17.4%				4.3%		
Other	93.1%	3.4%	3.4%							
Medical Geneticists	83.3%		16.7%							
Genetic Counselors	95.7%	4.3%								

All providers: n=29; Medical geneticists: n=6; Genetic counselors: n=23

Clinical Patient Care

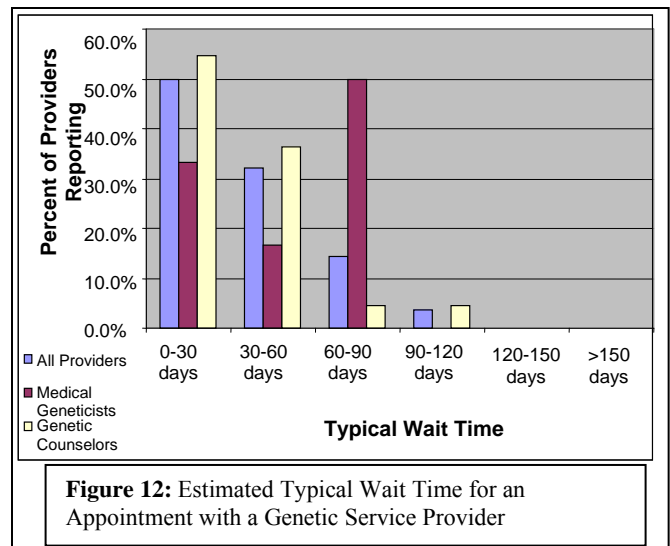
Clinical patient care is the professional activity to which genetic service providers devote most of their time. In 2006, a total of 3,376 patients were reportedly seen by a medical geneticist and 6,410 were seen by a genetic counselor. Given that some patients see both a medical geneticist and a genetic counselor during the same visit, there is definitely some overlap, though the degree of this is impossible to determine based on the data available.

Of the 9,786 total patients reported to be seen by a genetic services provider, over half (5899) were new outpatients and of those, 433 were seen in an outreach clinic. Providers reported seeing 3,307 “return” outpatients, 263 of them in outreach clinics. Another 580 patients were seen as inpatients (Table 7). On average, a medical geneticist saw 563 patients per year. An average genetic counselor saw 291 patients per year, with some counselors seeing far more than average and others seeing far fewer. Of the 22 counselors who reported seeing patients, only 8 saw new patients in an outreach setting, 7 saw returning patients in an outreach setting, and 11 saw inpatients.

Table 7: Estimated Number of Patients Seen by Genetic Service Providers in 12 Months

	All Providers		Medical Geneticists		Genetic Counselors	
	Total	Average (n)	Total	Average (n)	Total	Average (n)
New outpatients at primary site	5466	195.2 (n=28)	1570	261.7 (n=6)	3896	177.0 (n=22)
New outpatients at outreach site	433	30.9 (n=14)	273	45.5 (n=6)	160	20.0 (n=8)
Returning outpatients at primary site	3044	108.7 (n=28)	992	165.3 (n=6)	2052	93.3 (n=22)
Returning outpatients at outreach site	263	20.2 (n=13)	183	30.5 (n=6)	80	11.4 (n=7)
Inpatients	580	34.1 (n=17)	358	59.7 (n=6)	222	20.2 (n=11)
TOTAL	9786	349.5 (n=28)	3376	562.7 (n=6)	6410	291.4 (n=22)

The typical wait time for a patient to obtain an appointment with a genetics provider is less than 120 days for all responding providers in Wisconsin. Half report the wait time is less than 30 days for new patients, and more than half report a wait time of less than 30 days for returning patients (Fig. 5). Although it is more likely a patient will have to wait somewhat longer for an appointment with a medical geneticist versus a genetic counselor, half of the medical geneticists report patients typically have to wait 60 days or less to see them.



Of those patients with a scheduled appointment, most reportedly keep the appointment. Genetics providers report an average of one missed appointment per week, which totals approximately 10% of a provider’s appointments in a typical week (Table 8). Medical geneticists report an average of 2 missed appointments (12.5%) per week, while genetic counselors report an average of 1 per week (10%).

Table 8: Estimated Number of Scheduled Appointments Missed by Patients per Week by Provider Report

	All Providers	Medical Geneticists	Genetic Counselors
# Missed appointments/week			
Mean	1.25	1.60	1.13
Median	1	2	1
Mode	1	2	1
% Missed appointments/ week			
Mean	10.6%	12.5%	10.0%
Median	10%	12.5%	10.0%
Mode	10%	15%	10.0%

All providers: n=28; Medical geneticists: n=6; Genetic counselors: n=22

The patient population served by genetics providers may be classified in many different ways. For the purposes of this survey, providers were asked to classify their patients based upon age of patient, type of diagnosis (e.g. developmental delay, cancer, metabolic), racial and ethnic identification, insurance coverage, and source of referral.

Providers were first asked to define their patient population by age, in which the available selections were: newborns and infants, children and adolescents, adults (not pregnant), prenatal or reproductive adult patients, and other. Medical geneticists reported children and adolescents as making up the largest percentage of their patient population (Table 9). Over 80% reported children comprising 26 to 60% of their patient population, with other age groups making up less than 40% each. Genetic counselors were more varied in their responses. 17.4% reported 100% of their patients were adults. This is presumably due to a certain number of genetic counselors who specialize in counseling patients with hereditary cancer syndromes, a largely adult subgroup. However, most genetic counselors appear to see a wide range of patient types, as evidenced by the fact no one age group comprised more than 50% of the majority of counselors' patients.

Table 9: Percent of Patient Population Seen in Practice by Genetic Service Providers by Type of Patient

Type of Patient	Percent of Patient Population									
	0%	1-10%	11-25%	26-40%	41-50%	51-60%	61-75%	76-90%	91-99%	100%
Newborns & infants	24.1%	20.7%	24.1%	20.7%	6.9%	3.4%				
Medical Geneticists		16.7%	16.7%	50.0%		16.7%				
Genetic Counselors	30.4%	21.7%	26.1%	13.0%	8.7%					
Children & adolescents	20.7%	13.8%	13.8%	20.7%	13.8%	3.4%	10.3%			3.4%
Medical Geneticists			16.7%	50.0%	16.7%	16.7%				
Genetic Counselors	26.1%	17.4%	13.0%	13.0%	13.0%		13.0%			4.3%
Adults (not pregnant)	3.4%	34.5%	17.2%	17.2%	6.9%				6.9%	13.8%
Medical Geneticists		33.3%	50.0%	16.7%						
Genetic Counselors	4.3%	34.8%	8.7%	17.4%	8.7%				8.7%	17.4%
Prenatal/ Reproductive patients	44.8%	17.2%	6.9%	13.8%	6.9%			6.9%	3.4%	
Medical Geneticists	16.7%	33.3%	33.3%	16.7%						
Genetic Counselors	52.2%	13.0%		13.0%	8.7%			8.7%	4.3%	
Other	96.6%	3.4%								
Medical Geneticists	100%									
Genetic Counselors	95.7%	4.3%								

All providers: n=29; Medical geneticists: n=6; Genetic counselors: n=23

Providers also defined their patient population by type of diagnosis. The possible selections for diagnosis included: Dysmorphology/birth defects/syndromes, Developmental delay/mental retardation, Metabolic conditions/newborn screening issues, Reproductive/prenatal issues, Cancer, Common/complex disorders, Adult-onset single gene disorders, and Other. The most common type of diagnosis reported was Dysmorphology/birth defects/syndromes (Table 10). A majority of providers (65.2%) saw at least some patients with this type of diagnosis, including 100% of medical geneticists. For the most part, medical geneticists reported seeing mostly patients with either Dysmorphology/birth defects/syndromes or Developmental delay/mental retardation, with the other types of diagnoses making up a minority of their patient populations. Genetic counselors saw patients with all types of diagnoses, with no clear majority of type among all counselors. Some genetic counselors reported seeing one type of diagnosis exclusively, including Dysmorphology/birth defects/syndromes (4.3%), Reproductive/prenatal issues (3.4%)

and Cancer (17.4%). A majority of genetic counselors reported seeing no patients with common/complex disorders or adult-onset single gene disorders.

Type of Diagnosis	Percent Patient Population									
	0%	1-10%	11-25%	26-40%	41-50%	51-60%	61-75%	76-90%	91-99%	100%
Dysmorphology/ birth defects/ syndromes	27.6%	17.2%	20.7%	6.9%	6.9%	6.9%		6.9%	3.4%	3.4%
Medical Geneticists			33.3%	33.3%	16.7%			16.7%		
Genetic Counselors	34.8%	21.7%	17.4%		4.3%	8.7%		4.3%	4.3%	4.3%
Developmental delay/ mental retardation	37.9%	10.3%	27.6%	10.3%	6.9%		3.4%		3.4%	
Medical Geneticists			50.0%	33.3%			16.7%			
Genetic Counselors	47.8%	13.0%	21.7%	4.3%	8.7%				4.3%	
Metabolic conditions/ newborn screening	41.4%	41.4%	6.9%	3.4%				6.9%		
Medical Geneticists	16.7%	66.7%		16.7%						
Genetic Counselors	47.8%	34.8%	8.7%					8.7%		
Reproductive/ prenatal issues	44.8%	20.7%	6.9%	10.3%	3.4%	3.4%		6.9%		3.4%
Medical Geneticists		66.7%	33.3%							
Genetic Counselors	56.5%	8.7%		13.0%	4.3%	4.3%		8.7%		4.3%
Cancer	44.8%	17.2%	3.4%	10.3%	3.4%				6.9%	13.8%
Medical Geneticists	33.3%	50.0%		16.7%						
Genetic Counselors	47.8%	8.7%	4.3%	8.7%	4.3%				8.7%	17.4%
Common/ complex disorders	58.6%	37.9%				3.4%				
Medical Geneticists		100%								
Genetic Counselors	73.9%	21.7%				4.3%				
Adult-onset single gene disorders	41.4%	44.8%	13.8%							
Medical Geneticists		100%								
Genetic Counselors	52.2%	30.4%	17.4%							
Other	96.6%								3.4%	
Medical Geneticists	100.0%									
Genetic Counselors	95.7%								‡4.3%	

All providers: n=29; Medical geneticists: n=6; Genetic counselors: n=23

‡Genetic counselor categorized "Bone dysplasia" patients as "Other"

Genetic service providers in Wisconsin reportedly do not see a racially or ethnically diverse patient population. A majority of providers (82.4%) report White or Caucasian individuals make up more than three-quarters of their patient population (Table 11). Individuals identified as belonging to any other defined racial category is reported by a majority of providers to make up 10% or less of their patients. Approximately 65% of providers also report non-Hispanic individuals comprise more than 90% of their patient population. 2005 data from the U.S. Census Bureau estimate Wisconsin's population to be 90.6% white, 6.4% black, 2.2% Asian, 1.3% American Indian, and >1.0% Pacific Islander or Middle Eastern. This data does not differentiate between those who report one racial category and those that report more than one (multiracial). The same data estimates 4.6% of the population is Hispanic, while 95.4% is non-Hispanic. The reports by Wisconsin genetic service providers indicate the racial and ethnic distribution of their patient populations is similar to that of the Wisconsin population as a whole.

Table 11: Percent of Patient Population Seen in Practice by Genetic Service Providers by Race and Ethnicity

Race/Ethnicity	Percent of Patient Population									
	0%	1-10%	11-25%	26-40%	41-50%	51-60%	61-75%	76-90%	91-99%	100%
Race										
American Indian/ Alaskan Native	24.1%	72.4%								
Arab or Middle Eastern Descent	31.0%	65.0%		3.4%						
Asian/ Southeast Islander	31.0%	58.6%	10.3%							
Black or African Descent	3.4%	69.0%	17.2%	6.9%	3.4%					
White or Caucasian				3.4%	3.4%	3.4%	17.2%	24.1%	48.3%	
Multiracial	31.0%	52.2%	6.9%	6.9%						
Other	89.7%	10.3%								
Unknown	89.7%	10.3%								
Ethnicity										
Hispanic	3.4%	69.0%	17.2%	6.9%	3.4%					
Non-Hispanic						3.4%	10.3%	17.2%	65.5%	3.4%

All providers: n=29; Medical geneticists: n=6; Genetic counselors: n=23

Insurance coverage in Wisconsin, and in the United States, is not uniform and varies from patient to patient. Providers were asked to estimate the percentage of their patients who are covered by private insurance, a managed care plan (e.g. an HMO or PPO), public insurance (e.g. Medicare/Medicaid), no insurance, or an unknown insurance type.

Table 12: Percent of Patient Population Seen in Practice by Genetic Service Providers by Type of Insurance Coverage

Type of Insurance	Percent of Patient Population									
	0%	1-10%	11-25%	26-40%	41-50%	51-60%	61-75%	76-90%	91-99%	100%
Private insurance										
Medical Geneticists	3.4%	17.2%	24.1%	24.1%	13.8%	13.8%	3.4%			
Genetic Counselors	4.3%	21.7%	26.1%	17.4%	13.0%	13.0%	4.3%			
Managed care										
Medical Geneticists	10.3%		20.7%	31.0%	10.3%	10.3%	6.9%	10.3%		
Genetic Counselors	16.7%		16.7%	33.3%	16.7%	16.7%				
Public insurance										
Medical Geneticists	3.4%	3.4%	20.7%	34.5%	17.2%	6.9%	13.8%			
Genetic Counselors	4.3%	4.3%	26.1%	26.1%	13.0%	8.7%	17.4%			
Uninsured										
Medical Geneticists	24.1%	65.5%	6.9%	3.4%						
Genetic Counselors	16.7%	33.3%	33.3%	16.7%						
Unknown insurance type										
Medical Geneticists	89.7%	10.3%								
Genetic Counselors	83.3%	16.7%								

All providers: n=29; Medical geneticists: n=6; Genetic counselors: n=23

A majority of patients are covered by some type of insurance. Over 89% of providers report that 10% or less of their patients are uninsured, including 100% of reporting genetic counselors (Table 12). However, 16.7% of medical geneticists report at least a quarter of their patients are uninsured. There appears to be a fairly even distribution of patients covered by private insurance, managed care plans, and public insurance. Approximately 27% of providers report at least half of their patients are covered by managed care plans, while about 17% and 20% report at least half are covered by private and public insurance, respectively. Only a small proportion of patients were reported to have an unknown insurance type.

Referrals to genetic services can come from a variety of sources. Providers estimated what percentage of their patients were referred by the following sources: medical geneticists, general physicians (e.g. pediatricians, family practice doctors), specialist physicians (e.g. oncologists, OB/GYN's), genetic counselors, the newborn screening program, local public health departments, schools/teachers/aides, early interventionists (e.g. Birth-to-3, physical therapy), self- or family referral, unknown, or other. The majority of referrals are provided by general physicians and specialty physicians (Table 13). Between 76% and 90% of a provider's patient population is referred by a generalist physician for about 10% of providers; the same can be said for a specialist physician as the referral source. At least 11% of all patients seen by a medical geneticist were referred by a specialist physician, and at least one-quarter were referred by a general physician. Genetic counselors were more likely as a group to have over half of their patient population referred by a specialist (43.3% vs. 16.7% of medical geneticists), possibly due to the fact genetic counselors specializing in prenatal or cancer counseling are more likely to receive referrals from oncology or obstetrics/gynecology. Other sources of referral were less common, but a small percentage of patient populations were referred by each source above to at least some genetic service providers.

Clinical Service Capacities

A major intention of this survey was to assess the existing service capacities of clinical genetics in Wisconsin. One of the primary contributors to capacity is adequate staffing. Providers were asked to first assess whether or not their center had too few, the right number, or too many of the following: medical geneticists, PhD geneticists, genetic counselors, support staff, and other. The providers also had the option of marking "unsure" as a response. If their center had too few of a certain staff type, providers were then asked to estimate how many staff members would be necessary to meet capacity.

Referral Source	Percent of Patient Population									
	0%	1-10%	11-25%	26-40%	41-50%	51-60%	61-75%	76-90%	91-99%	100%
Medical geneticists	48.3%	44.8%	6.9%							
Medical Geneticists	16.7%	50.0%	33.3%							
Genetic Counselors	56.5%	43.5%								
General physicians	3.4%	10.3%	24.1%	24.1%	17.2%	6.9%	3.4%	10.3%		
Medical Geneticists				50.0%	33.3%	16.7%				
Genetic Counselors	4.3%	13.0%	30.4%	17.4%	13.0%	4.3%	4.3%	13.0%		
Specialist physicians	3.4%	6.9%	17.2%	13.8%	20.7%	10.3%	13.8%	10.3%	3.4%	
Medical Geneticists			33.3%	16.7%	33.3%		16.7%			
Genetic Counselors	4.3%	8.7%	13.0%	13.0%	17.4%	13.0%	13.0%	13.0%	4.3%	
Genetic counselors	34.5%	58.6%	3.4%	3.4%						
Medical Geneticists	16.7%	83.3%								
Genetic Counselors	39.1%	52.2%	4.3%	4.3%						
Newborn screening	62.1%	20.7%	10.3%				3.4%	3.4%		
Medical Geneticists	50.0%	33.3%	16.7%							
Genetic Counselors	65.2%	17.4%	8.7%				4.3%	4.3%		
Local public health	75.9%	24.1%								
Medical Geneticists	33.3%	66.7%								
Genetic Counselors	87.0%	13.0%								
School/ teachers/ aides	69.0%	27.6%	3.4%							
Medical Geneticists		83.3%	16.7%							
Genetic Counselors	87.0%	13.0%								
Early interventionists	58.6%	37.9%		3.4%						
Medical Geneticists		100%								
Genetic Counselors	73.9%	21.7%		4.3%						
Self- or family referral	10.3%	48.3%	34.5%	3.4%	3.4%					
Medical Geneticists		66.7%	33.3%							
Genetic Counselors	13.0%	43.5%	34.6%	4.3%	4.3%					
Other	89.7%	6.9%								3.4%
Medical Geneticists	83.3%	16.7%								
Genetic Counselors	91.3%	4.3%								◇4.3%
Unknown source	100%									
Medical Geneticists	100%									
Genetic Counselors	100%									

All providers: n=29; Medical geneticists: n=6; Genetic counselors: n=23

◇ Genetic counselor does not receive new referrals; sees same patients as part of ongoing study

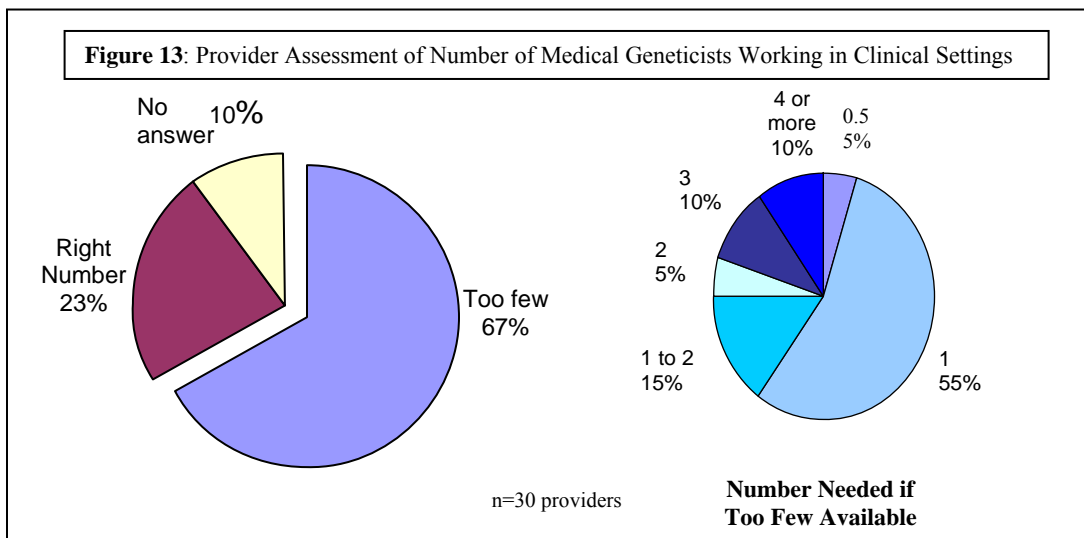
In every category, all responding providers either answered “too few” or “right number.” The option “too many” was never selected by a respondent (Table 14). A majority of providers (66.7%) indicated there are too few medical geneticists on their staff. In the case of both genetic counselors and support staff, 60% of responding providers indicated too few are employed at their particular institution. Only 23.3% of providers said more PhD geneticists were needed on staff.

Table 14: Genetic Service Providers Assessment of Current Staff Capacity at Their Institution

Type of Staff	Staff Capacity				
	Too Few	Right Number	Too Many	Unsure	No answer
Medical geneticists	66.7%	23.3%			10.0%
PhD geneticists	23.3%	13.3%		36.7%	26.7%
Genetic counselors	60.0%	36.7%			3.3%
Genetic support staff	60.0%	36.7%			3.3%
Other	20.0%	23.3%		13.3%	43.3%

The two-thirds of respondents who believe more medical geneticists are needed at their facilities varied in the number of geneticists they assess would be needed to reach capacity. Most (55%) think that one additional medical geneticist would be sufficient (Fig. 13). However, 30% of respondents think anywhere from 1 to 3 would be needed, and 10% believe anything under an additional 4 medical geneticists would be insufficient.

n= 30 providers



In order to tease out just how many medical geneticists would be needed in the state of Wisconsin in order to meet capacity as defined by genetic service providers, the data would need to reflect the fact that several responding providers work together in the same facility. The providers' data was sorted by zip code and any surveys received from the same zip code were assumed, for the purposes of this data manipulation, to be from providers working at the same facility. While this may not necessarily be true in all cases, the assumption is reasonable for estimation purposes based on the general distribution of providers in the state. If one zip code appeared more than once, the responses to the number of medical geneticists needed were averaged. If any respondent gave an answer with more than one value (e.g. 1 to 2), the highest value was used to calculate the average. Table 15 shows the results of this data manipulation.

Table 15: Average Number of Medical Geneticists Needed by Zip Code

Zip code	Number of responses from zip code	Average number of medical geneticists needed by report
53188	1	0
53201	1	1
53215	1	1
53226	5	1
53703	1	1
53704	1	2
53705	9	2.375
53715	1	1
53717	1	2
54307	2	0.75
54308	1	0
54449	4	0.5
54601	1	0
54956	1	0
Total number needed:		12.625

If assuming one facility per zip code, it appears most genetic service centers require one additional medical geneticist. However, one center’s providers believe two or three medical geneticists would be needed in order to meet capacity. Based on this analysis, a total of 12 to 13 medical geneticists would be needed in the state of Wisconsin in order for all facilities offering clinical genetic services to be adequately staffed.

More genetic counselors would also be needed to reach capacity. 67% of providers indicated 1 to 2 genetic counselors would likely be sufficient to meet the demands of their facility (Fig. 14). A third of providers, though, felt at least three and possibly four or more genetic counselors would be necessary to meet clinical capacity. The responses did not distinguish between the need for part-time versus full-time counselors.

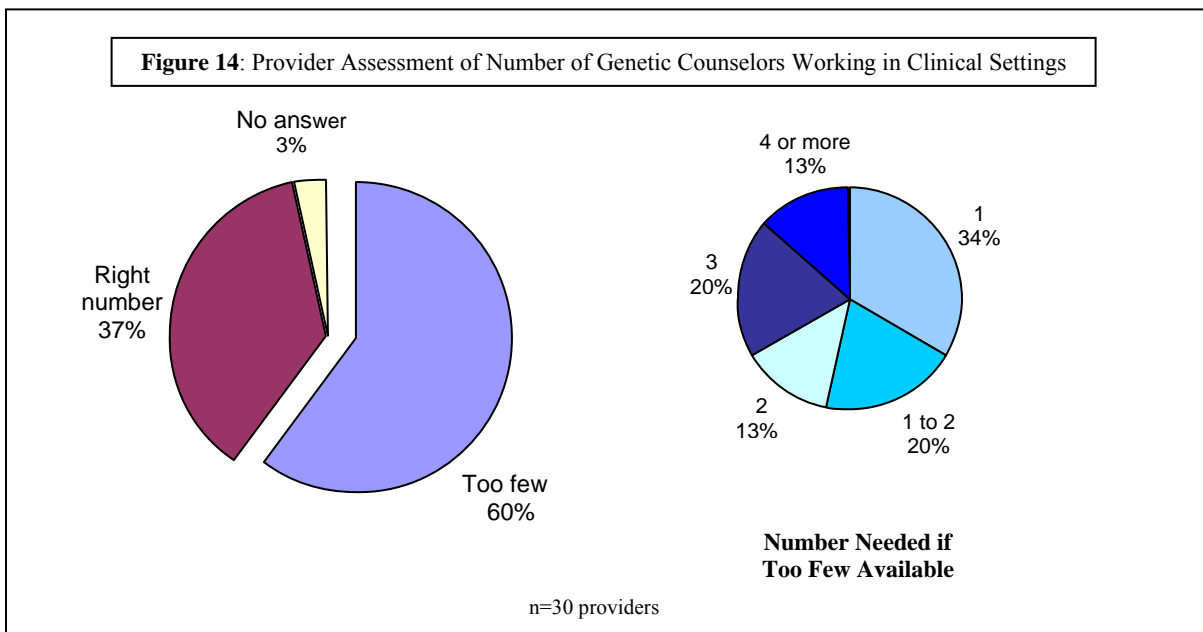


Table 16: Average Number of Genetic Counselors Needed by Zip Code

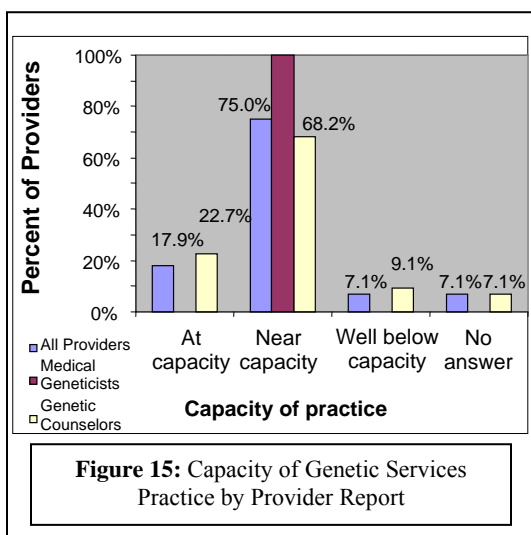
Zip code	Number of responses from zip code	Average number of genetic counselors needed by report
53188	1	0
53201	1	3
53215	1	0
53226	5	2.25
53703	1	1
53704	1	3
53705	9	4.33
53715	1	0
53717	1	4
54307	2	0
54308	1	0
54449	4	1
54601	1	1
54956	1	1
Total number needed:		20.583

In order to estimate just how many more genetic counselors would be necessary to fill these requirements, the same type of data manipulation and analysis as was performed with the medical geneticist data was completed with genetic counselor data (Table 16).

If one zip code per facility is once again assumed, it appears the needs of centers in terms of genetic counselors are variable; some centers would only require one counselor, while others would require several more. In order for all medical genetic service facilities in Wisconsin to have a full staff of genetic counselors, around 20 to 21 more counselors would reportedly be needed. Again, there was no specification as to whether the necessary counselors would be part-time or full-time.

Providers were asked to further assess existing service capabilities by agreeing with one of the following three statements:

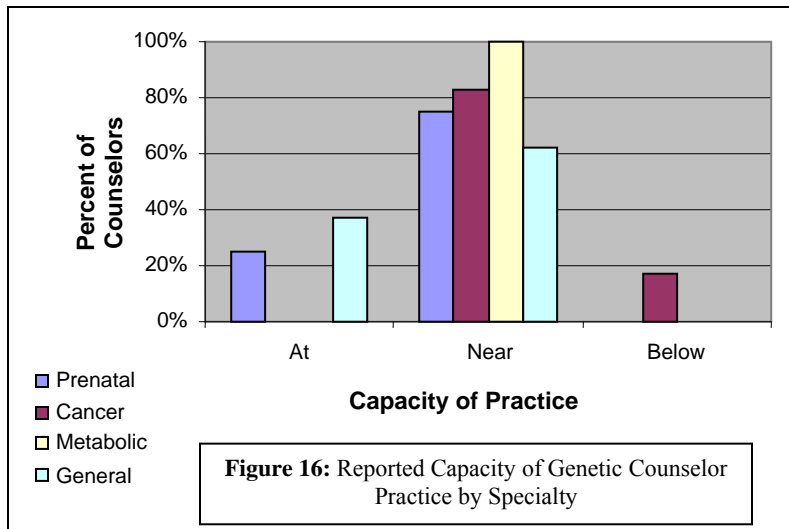
1. I cannot accept any additional patients, my practice is at capacity
2. I can accept some additional genetics patients, my practice is near capacity
3. I can accept many additional genetics patients, my practice is well below capacity



In response, 70% of genetics providers (including 100% of medical geneticists and 62.5% of genetic counselors) agreed with the second statement. 16.7% of providers felt their practice was at capacity, and 6.7% felt it was well below capacity (Fig. 15).

As genetic counselors tend to practice within certain “specialties,” the capacity of practice was analyzed separately for counselors who specialized in one of the following diagnosis types: general genetics, metabolic genetics, prenatal diagnosis, and cancer genetics. A counselor was determined to be in metabolic, prenatal, or cancer specialty practice if 50% or greater of their patient population consisted of a

single type of diagnosis related to those respective areas. For a general genetics specialty, the counselor was specialized if greater than 50% of their patient population *excluded* diagnoses related to reproductive/prenatal issues, cancer, or metabolic conditions.



Using these criteria, 20 of the 24 genetic counselors (83%) had a specialty of some kind. Four counselors of the 20 (20%) specialize in prenatal diagnostics, six (30%) specialize in cancer genetics, two (10%) specialize in metabolic genetics, and eight (40%) can be considered specialists in general genetics. Once categorized thus, the counselors' reports of practice capacity was analyzed (Fig. 16). Prenatal counselors reported themselves to be

either at or near capacity, with a majority (75%) reporting to be near capacity. Cancer counselors were the only group to report being below capacity at all; however, this was a minority response, as most (83%) report being near capacity. Both metabolic counselors reported being near capacity in their practice. General counselors were more likely, as a group, to report being at full capacity. While nearly 63% of general counselors are reportedly near capacity, over one-third (37.5%) of those specializing in general genetics have reached practice capacity.

All medical geneticists reported being near capacity in their practice; as such, no further analysis of the data was undertaken.

Clinical Outreach Services

Of the thirty genetic service providers who responded to the survey, 15 of them provide clinical genetics outreach services (defined for the purposes of this survey as any location not at the provider's primary patient care practice). This included all 6 of the medical geneticists, and 9 genetic counselors.

Genetics providers individually staff a wide range of outreach clinics; anywhere from 1 to 36 clinics per year. Medical geneticists averaged over 15 clinics per year, with most attending 6 outreach clinics. Genetic counselors averaged nearly 12 clinics per year, though the mode for the group was 4. Clinics were typically staffed for 6-7 hours per day, meaning that genetic service providers spent an average of 94.5 hours in outreach clinics per year (not including travel time). As a collective whole, genetic service providers spent 1,418 hours in outreach clinics; medical geneticists logged 894 hours, while genetic counselors reported a total of 524 hours. Most of these hours took place in multiple specialty clinics (setting reported by 10 providers), followed by hospitals and managed care organizations (4 reports each), then single specialty clinics (3 reports), and one report each of an academic medical center setting and a government agency.

Genetic service providers see patients in outreach clinics all over Wisconsin, as well as in locations in Ohio and Michigan. A total of 18 cities were reported to host an outreach clinic at least once during the course of a year (Table 17). While many of these clinics were held in the southeastern and central-eastern areas of Wisconsin, a few were scattered throughout the northern and western regions of the state (Fig. 17). Clinical genetic services may be found, either regularly or on an outreach basis, in fifteen separate counties.

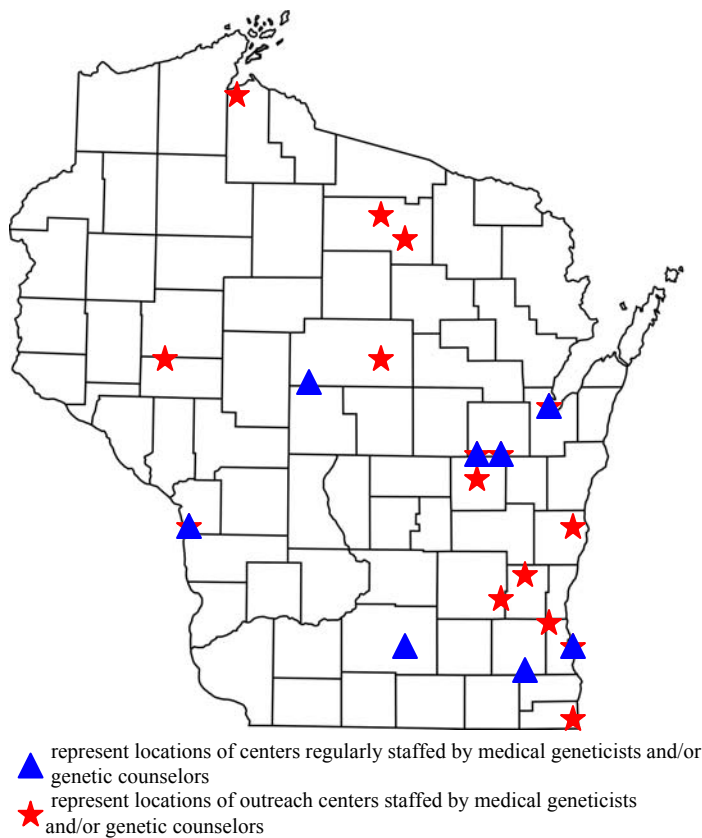


Figure 17: Map Representing Locations of Clinical Genetic Services in Wisconsin

Table 17: Cities in Which Genetic Providers Report Staffing Outreach Clinic(s)

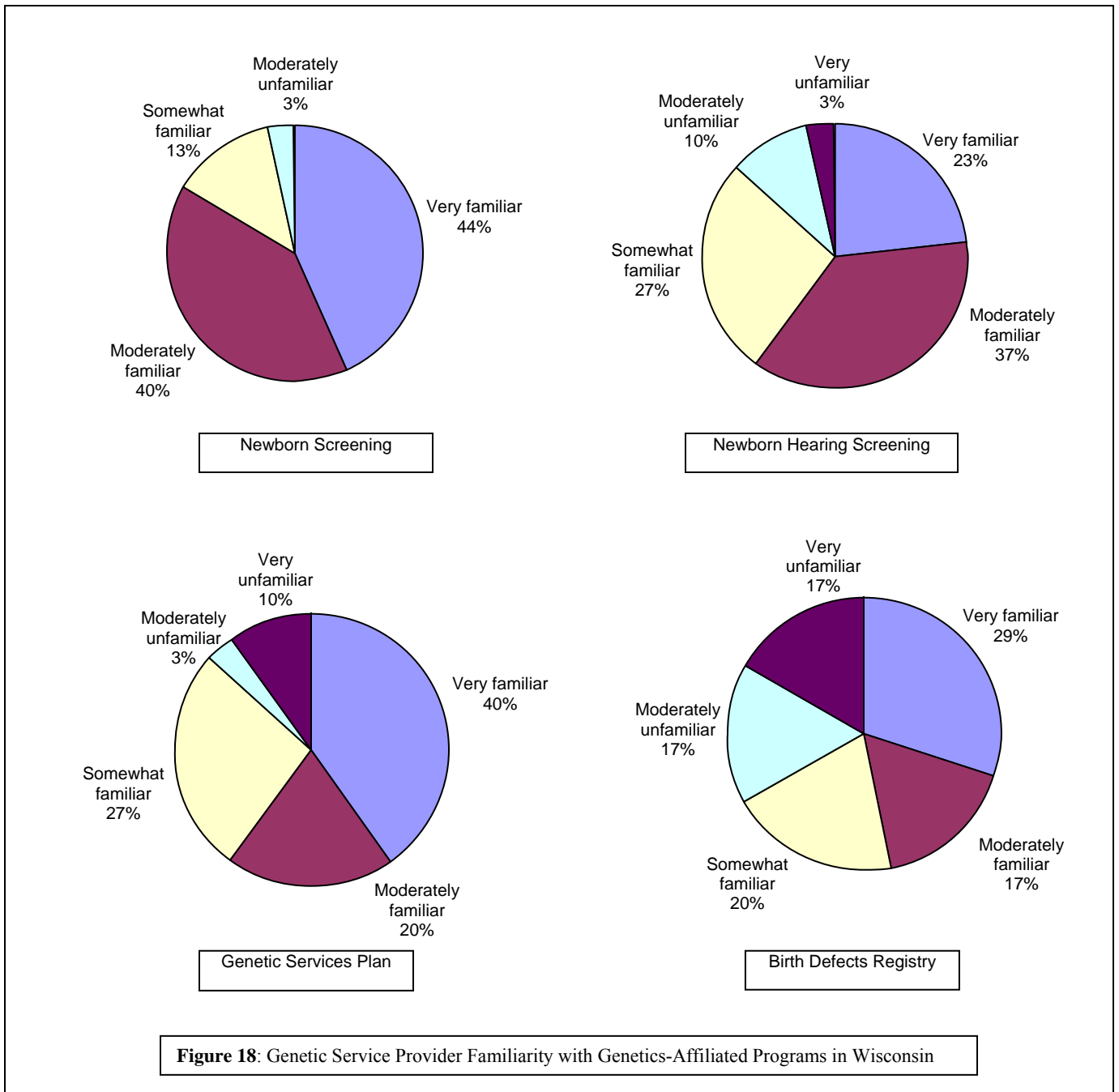
City	Number of Visits/Year
Akron, OH	8
Appleton, WI	3
Ashland, WI	6
Brown Deer, WI	5
Eau Claire, WI	18
Grand Rapids, MI	6
Green Bay, WI	12
Hartland, WI	24
Kenosha, WI	12
La Crosse, WI	1
Milwaukee, WI	14
Minocqua, WI	13
Neenah, WI	12
Oshkosh, WI	12
Rhinelander, WI	6
Sheboygan, WI	20
Slinger, WI	12
Wausau, WI	14
Other	1 to 2

Visits include all those made by any medical geneticist(s) and/or genetic counselor(s)

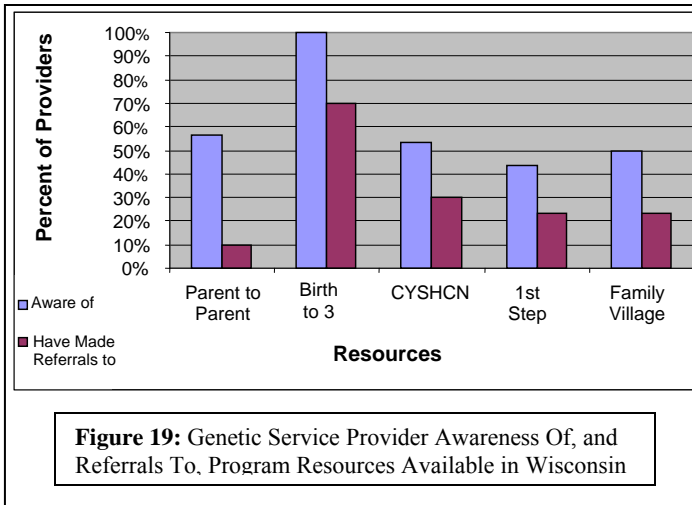
Genetics in Wisconsin

Providers were asked about their familiarity with certain programs in Wisconsin which have some affiliation with clinical genetic services: the Wisconsin Newborn Screening Program, the Wisconsin Early Hearing Detection and Intervention (Newborn Hearing Screening), the Genetic Services Plan for Wisconsin, and the Wisconsin Birth Defects Prevention and Surveillance Registry. Possible answers were provided in a five item Likert scale.

The program with which providers acknowledged the most familiarity was the Newborn Screening Program: 84% of providers were very or moderately familiar with the program, while only 3% were moderately unfamiliar and zero were very unfamiliar. Over half of providers (60%) were very or moderately familiar with the Newborn Hearing Screening Program, but 10% were moderately unfamiliar and 3% were very unfamiliar. Similar levels of familiarity were reported for the Genetic Services Plan: 60% were very or moderately familiar, while 13% were moderately or very unfamiliar. The Birth Defects Registry was the program with which providers were the least familiar: only 29% were very familiar, 17% were moderately familiar, 20% were somewhat familiar, and 34% were moderately or very unfamiliar (Fig. 18).



Providers were also asked about certain resources available in Wisconsin which may be beneficial to their patient populations. Those resources included: Parent-to-Parent of Wisconsin, Birth-to-3 Early Intervention Program, Regional Children & Youth with Special Health Care Needs Centers, the Wisconsin First Step Hotline, and Family Village. These resources were selected as they are designed to reach a fairly broad population which would certainly include individuals with genetic diagnoses.



The Birth to 3 Program had 100% recognition by all providers, though only 70% had reported making at least one referral (Fig. 19). Many of those who had not made referrals reported serving a primarily adult population or have been in the profession a short time. At least half of all providers were aware of the other programs listed, the exception being 1st Step (43% aware), a program which aids individuals with special needs in making transitions from childhood to adulthood. Referrals

to other programs were low when compared to reported referrals to Birth to 3. Only 30% of providers report making a referral to Regional Children & Youth With Special Health Care Needs Centers, while just over 20% report referring to either 1st Step or Family Village. Just 10% have made referrals to the Parent to Parent of Wisconsin program. Survey respondents were not given the opportunity to expound upon reasons for referral, or why certain programs received more referrals than others.

Provider Commentary: Genetics in Wisconsin

The final section of the survey asked for responder comments to three questions relating to genetic service provision in Wisconsin:

1. **In your opinion, what are the primary barriers to providing sufficient and quality medical genetic services to residents in Wisconsin?**
2. **If telemedicine genetic service capabilities (i.e. providing clinical service through phone and/or video link) were to become available in Wisconsin, would you utilize them? Why or why not? In what capacity can you see these services being used, and how useful would they be?**
3. **In your opinion, what are the primary issues genetics providers in your field will face over the next 5 to 10 years in regards to the provision of genetic services in Wisconsin?**

Of those providers returning a survey, 25 responded with comments to questions 1 and 2, and 23 responded to question 3. For each question, similar responses were grouped into general categories. As respondents were not confined to one comment per question, several individuals had responses which fell into two or more categories.

The first question regarded primary barriers to service provision in Wisconsin. Nearly half (48%) of those who answered this question listed the small number of genetic service providers as a major barrier to service (Table 18).

“Very few providers – many people in Wisconsin live several hours from a genetic counselor or geneticist.”

“Not enough genetics providers and not enough funding to hire adequate numbers.”

Table 18: Primary Barriers to Provision of Genetic Services by Provider Report

Primary Barriers to Service	Number of Respondents Listing Barrier	Percent of Respondents Listing Barrier (n=25)
Small number of providers	12	48.0%
Lack of patient insurance coverage	10	40.0%
Geographic distribution/lack of access to services	7	28.0%
Lack of awareness of services available	6	24.0%
Lack of knowledge/understanding of services	6	24.0%
Primary care physicians do not refer to genetics	5	20.0%
Lack of funding for centers or staff	4	16.0%
Lack of commitment from institutions	3	12.0%
Long wait times for appointments	2	8.0%
Lack of licensure by state for genetic counselors	2	8.0%
Patient fear of stigmatization/discrimination	2	8.0%
Other	3	12.0%

Another 40% cited the lack of patient insurance coverage for genetic consultations and testing:

“Too much time spent battling with insurance for referrals or authorizations for testing”

“Several insurance carriers exclude genetic counseling and testing regardless of medical necessity.”

Similar numbers of respondents commented on the lack of awareness of the services available in the state, the lack of knowledge and understanding of these services, and the lack of referral to services by primary care physicians (28%, 24%, and 24%, respectively).

“People are not willing to travel to the ‘big city’ to receive care.”

“Patients and physicians do not see the importance of genetic services and how it will impact case management.”

Some respondents mentioned a lack of funding for genetic centers and staff, a lack of commitment from institutions with which those centers are associated, long wait times for appointments, a lack of state licensure for genetic counselors, and patients’ possible fear of stigmatization or discrimination. Three other factors were listed by one provider each and were thus grouped in the “Other” category: no in-state labs accept Medical Assistance, too much time is spent on administrative work, and only centers associated with medical geneticists receive referrals.

“Medical institutions view clinical genetics as a ‘money-loser’ and an unnecessary component of quality care.”

“Genetic counselors currently unable to get a license, tremendously limited reimbursement for genetic counseling services.”

The second question inquired as to the potential use of telemedicine for clinical services. A majority of respondents (68.0%) indicated they would use telemedicine as defined, and 16.0% of respondents reportedly already do so (Table 19, Fig. 20). Some indicated telemedicine would be useful only under certain conditions, e.g. to overcome geographic barriers or for screening patients.

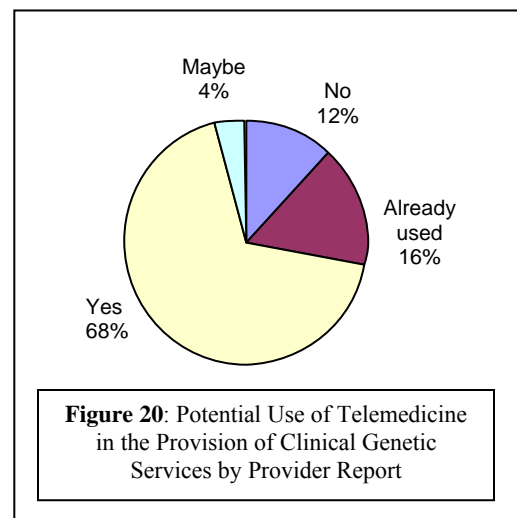
“It would be useful for at least screening long-distance referrals or to alternate with face-to-face outreach clinics. This would save travel time and make it more feasible to ‘see’ patients more than twice a year from up north. I don’t think they will replace traditional clinics, but could help supplement.”

“I think these services could be very useful for follow-up visits and counseling sessions – sessions which require predominantly conversations and little physical exam.”

Three respondents (12.0%) indicated they would not use telemedicine, citing an inability to bill or its impracticality in a particular patient population.

Table 19: Potential Use of Telemedicine in the Provision of Clinical Genetic Services by Provider Report

Use Telemedicine?	Number of Respondents	Percent of Respondents (n=25)
Yes	17	68.0%
To overcome geographic barriers	6	24.0%
If no physical exam needed	3	12.0%
If funding available	3	12.0%
For screening patients	2	8.0%
To give test results to referrers	1	4.0%
For urgent consults	1	4.0%
No	3	12.0%
Unable to bill	1	4.0%
Impractical for patient population	1	4.0%
Maybe	1	4.0%
Already in use for counseling purposes	4	16.0%



The final question asked respondents to identify those issues they believed would be most important in the field of genetic service provision in the near future. A majority (52.2%) commented on the shortage of service providers, particularly geneticists (Table 20).

“Number of available geneticists is limited, pay scale for genetics providers is not sufficient to recruit practitioners.”

“Getting enough trained clinical geneticists as the older generation retires.”

A slightly smaller percentage, 47.8%, named insurance and reimbursement difficulties as a major concern.

“... finding mechanisms of funding clinical and laboratory services that do not exclude the underinsured.”

“How to ensure that funding is available, both for MD’s and GC’s who nearly all provide care that cannot be fully self-sustaining”

Others cited issues like educating the community about the “new genetics,” the ability of physicians and patients to interpret genetic information, and accommodating patients with “common conditions” (e.g. cancer, heart disease, diabetes):

“As genetic information and availability of genetic testing for common disorders expands, it will be difficult to accommodate the number of patients referred. [Genetic service providers] need to work closer with primary care physicians to educate about more basic genetic information and to help them integrate genetic information into their practice.”

Table 20: Future Issues to Be Addressed in the Provision of Clinical Genetic Services by Provider Report

Future Issue	Number of Respondents	Percent of Respondents (n=23)
Shortage of service providers	12	52.2%
Insurance/reimbursement difficulties	11	47.8%
Genetic counselor licensure & billing	6	26.1%
Educating public & medical community about the “new genetics”	5	21.7%
Ability of primary care physicians & patients to interpret information	4	17.4%
Cost of care	4	17.4%
Ability to expand to meet demand	3	13.0%
Accommodating patients with “common conditions”	2	8.7%
Other	4	17.4%

A few issues did not quite fit into the defined categories, but were mentioned by at least one respondent. These included the expansion of molecular genetics into primary care practice, helping patients handle transitions in care, concerns about specialists who try to “do it themselves” rather than utilize genetic services, and ensuring underserved populations are not excluded.

Discussion

It is difficult to draw definite conclusions from the results of the medical provider survey due to the low response rate. However, some definite trends were apparent which may help guide the genetics community in establishing stronger and more effective collaborations with other medical practitioners. The information obtained from clinical genetic service providers was often not based on hard data. Many of the questions asked for estimates and opinions of the providers. None of the results collected in this study are based on analysis of clinic records or number tabulations. Answers were also open to provider bias and personal belief. As such, it is impossible to know how accurately these results reflect the true status of genetic services provision in Wisconsin. However, certain general conclusions can be tentatively drawn in the hopes they may be applied to future clinical service policy.

Genetic Service Provision

A large majority of medical providers in Wisconsin responding to this survey have made referrals for their patients to obtain genetic consultation or counseling, some several referrals in one year. The indication for referral is variable, but it does appear as though medical providers are more likely to refer to genetics if the patient has a birth defect, is considered dysmorphic, or has a family or personal history of a genetic condition. A personal or family history of certain types of cancer also makes referral more likely. Medical providers report being less likely to refer a

patient with behavioral problems, infertility, or overgrowth. Genetic service providers report the most common reason for referral to their clinics as being dysmorphology/birth defects/syndromes, followed closely by developmental delay/mental retardation. The least common reasons for referral for patients seen in genetics clinic are common or complex disorders, and adult single-gene disorders.

Other factors play into the decision to refer. Based both on answers to direct questions and those asking for non-structured opinions, medical providers seem most likely to refer if they believe the genetic consultation will be directly beneficial to their patient and if there are limited barriers to accessing services. Direct benefit to the patient likely includes the availability of treatment and definite management guidelines, as well as information regarding recurrence risk and consequences for other family members. Medical providers may decide not to refer to genetics if the patient is not interested or declines services. Some providers view a genetic consultation as having the potential to cause anxiety in a patient or overwhelm them with information. While it is not apparent from the results of this survey as to whether or not such a belief would prevent a provider from offering a referral to genetics, it is a distinct possibility. Genetic service providers have expressed concern that a lack of understanding about genetic services, as well as patient fears about stigmatization or discrimination, might prevent people from obtaining services which may be beneficial to them. Patient and medical provider fears in this area are understandable, and it is up to the genetics community to offer education and assurance, especially in regards to those fears which are largely based on misconception.

It does not appear as though a lack of available services is perceived as a barrier to genetic services by most medical providers. Some medical providers still remain unsure about how to refer appropriately, and others voice concerns about referring patients who may be restricted by cost, but most know where those referrals should be directed, at least in regards to the major service centers. However, nearly 84% of providers responding to this survey were unaware of outreach genetic services as defined in the survey. Genetics outreach clinics have been established throughout Wisconsin. At this point, patients may receive genetic services in fifteen different Wisconsin counties. Outreach clinics are available several days a year in the most underserved areas of Wisconsin, which are primarily in the northwest. Medical providers in those areas especially should be aware of outreach services, as they are designed to be most beneficial to their patient population. However, these outreach clinics, while decidedly more convenient than travel to the major centers for many, are only available on certain days in certain locations. It is certainly conceivable some people may be unable to travel on particular days to particular clinics. Thus, there is still a proportion of the Wisconsin population without easy access to genetic services. Innovative solutions have been proposed for this dilemma, including the development of telemedicine. There are definite barriers to telemedicine, including being unable to bill for services and difficulties if a physical exam is required. It has yet to be decided whether future efforts should be concentrated on overcoming these particular barriers, or if a different solution altogether would be more practical.

Cost of Genetic Services

The decision to utilize a particular medical service or procedure is often dependent upon an individual's insurance coverage; genetic services are no exception. Genetic service providers report a majority of patients receiving clinical genetic services as being insured, be it public or private insurance. This survey did not address to what extent coverage of those services is provided, nor the extent of coverage for genetic testing, whether diagnostic, pre-symptomatic, or for carrier status. Such data may be important for future policy, as 40% of respondents to this survey list lack of insurance coverage as a major barrier to providing service. In addition, some

medical providers have acknowledged insurance limitations as a reason not to refer to genetics, and still others list prohibitive costs and a lack of insurance coverage as a disadvantage of genetics consultation for their patients.

Genetic counseling is a service regularly excluded from insurance coverage unless provided by a licensed medical professional. Licensure for genetic counselors is on a state-by-state basis and is not currently available in Wisconsin, though efforts are underway to introduce legislation which would change that. The licensing of genetic counselors would have a significant effect on the provision of genetic services. First of all, it would offer a higher level of protection to consumers. Only those individuals qualified to practice genetic counseling would be able to receive a license and provide care. These individuals would be required to achieve the appropriate level of education and training, and adhere to a professional code of ethics. Licensure would also allow genetic counselors to bill for services, which would enable more institutions to offer genetic counseling services, thus enhancing the public's access to qualified practitioners. As mentioned previously, a shortage of genetic counselors in the state will not likely be due to a lack of trained professionals, but rather a lack of available positions. Licensure for genetic counselors is a complicated topic, but one which could have a tremendous impact on improving the provision of genetic services in Wisconsin, including better insurance coverage for genetic services.

Of course, even if genetic services were wholly covered, some providers (both genetic and non-genetic) would be sure to remain concerned about the possibility of insurance discrimination. While documented cases of discrimination are few and far between, Wisconsin has been proactive in addressing this issue before it becomes problematic. Two state statutes are currently in place to address the use of genetic information (ss. 631.89 and ss. 942.07, Stats.). A full discussion of these statutes, including their benefits and limitations, warrant more space than can be devoted here. In short, these statutes offer a certain measure of protection but do not completely alleviate the possibility of insurance discrimination. The subject is definitely concerning to medical providers, and likely to patients as well. Thus, insurance discrimination, in conjunction with a perceived lack of coverage for medical genetic services, puts issues related to insurance at the top of any priorities list in addressing genetic services in Wisconsin.

The cost of genetic services is an issue which includes more than just insurance coverage and reimbursement for services. However, many of these cannot be addressed without first resolving issues within the area of insurance coverage. Genetic services cannot be offered by many institutions because, as of now, funding is not available to cover the cost of these services. Funding will not be available for genetic services until genetics providers can receive reimbursement for the services provided. Reimbursement for services provided will not be possible until insurance carriers, both private and public, cover all medically necessary genetic tests and services. Coverage of medically necessary genetic tests and services is contingent upon many things, including licensure of practicing genetic counselors and demonstration of the utility of genetic testing. In addition, the issue of insurance discrimination must be satisfactorily addressed before many physicians and patients will even be comfortable utilizing medical genetic services.

Providers of Genetic Services

Providers are generally highly trained professionals, Caucasian, and non-Hispanic. Most genetic counselors are female, and most medical geneticists are male. The medical geneticist population is also significant for the age of its members, in that many geneticists are reaching retirement age and may not be in clinical practice for much longer. The number one barrier to provision of genetic services as reported by survey respondents is the small number of providers. The

prospect of this number becoming even smaller as medical geneticists near retirement is alarming, as recognized by the 52% of respondents who list a shortage of service providers as an issue to be addressed in the future. In order for Wisconsin to provide its residents with the necessary and adequate level of clinical genetic services, this issue must take priority in guiding future policy.

Although a majority of provider time is spent in clinical care of patients, as little as 10% or as much as 75% of that clinical time may be spent in actual face-to-face contact with patients. Clinic time must also be devoted to preparation and follow-up, two activities which can easily consume a majority of a provider's time spent in clinic. It may be that greater support service is needed at institutions which house a genetics program to assist with these tasks. Service providers apparently agree, as a majority assesses their institution as having too few individuals employed as genetics support staff. The shortages of both providers and support staff likely contribute to the maximum capacity of clinical services.

Clinical Service Capacities

A majority of providers in the state indicate their institutions currently employ too few medical geneticists, genetic counselors, and genetic support staff in order to adequately provide clinical services. Estimates demonstrate an additional 12 to 13 medical geneticists would be needed to meet clinical demands, a startling number when one considers there were only 15 practicing medical geneticists in the state at the time of this survey. In addition, an estimated 20 to 21 genetic counselors would need to be added to those 47 practicing at the time of the survey in order to meet demand. In short, the number of medical geneticists in practice in Wisconsin would essentially need to double, and the number of genetic counselors would need to increase by over 40% in order to adequately meet the existing clinical service demand. However, in estimating the number of medical geneticists and genetic counselors required to adequately meet staffing capacities in Wisconsin, it is assumed no new facilities will offer genetic services. If any hospitals or medical centers in the state choose to begin offering clinical genetic services of any type, even more medical geneticists and/or genetic counselors will be required.

Nearly 93% of survey respondents report already being near or at capacity in their practice; either no new patients can be accepted without diminishing quality of service, or very few can. There appears to be an exception for some genetic counselors specializing in cancer counseling, though a majority of these counselors still report being near practice capacity at this point. These numbers demonstrate the very real shortage of genetic service providers in the state of Wisconsin, and the pressing need for real solutions.

Education of Medical Providers

Genetics is a complicated subject. Most medical providers have a very basic knowledge of medical genetics, having received little to no training in the subject and very little exposure to continuing education regarding developments in the field. Until recently, the domain of medical genetics has been "rare disorders" – the type of condition a general physician may stumble upon once in their entire career. However, advances in molecular genetics have begun to firmly define the role genetics play in the inheritance and manifestation of common conditions, including cancer, diabetes, and heart disease. Genetics is now an area of medicine of which *every* medical provider must be aware, which a majority of those providers responding to this survey recognize, and many commented upon:

"Education, education, education . . . I know I am missing things!"

“With the rapid proliferation of genetics knowledge, it is difficult to keep up with and offer adequate information for patients.”

“Likely an underutilized service, not something physicians feel comfortable with, could use education”

As mentioned previously, there also remain many misconceptions and fears surrounding genetics, which may be a possible barrier to service. While some of these fears are fully justified, some are based on past mistakes made by early geneticists. The shadow of the eugenics movement still looms large over the field. Some medical providers articulated this by offering comments such as the following:

“I remain suspicious of this sub-field. If used to help treat disease, then wonderful. If it is used to promote an ideology, it is anti-Hippocratic, and is a residual philosophy of social Darwinism and Nietzschean Ubermenschism. If a woman doesn’t abort her positive triple-screened baby, then geneticists will furrow their brow, wondering why this woman is so unenlightened – the handicapped child will only bring burdens to the rest of society, and will not contribute to the good of the economy.”

“Our knowledge should be used to cure, prevent, and ameliorate the effects of disease, not as a search and destroy mission as it so often is in the area of prenatal genetic diagnosis today.”

Other medical providers worry about the possibility of insurance discrimination or insurance profiling, as mentioned in a previous section. Still others believe a genetics consultation will only serve to heighten a patient’s or family’s anxiety, or place a stigma on diagnosed individuals. Educating physicians about methods to reduce anxiety or cope with stigma could be beneficial, as no one would deny these elements are present in medical genetics (and in other fields of medicine as well).

The means to educate medical providers presents a challenge. Providers in all areas of medicine are struggling to keep up with advances while still providing quality patient care. The demands placed on practicing physicians can be overwhelming, and may leave very little time to educate oneself about advances in other fields. It is not a lack of interest or ability to understand which holds them back, it is a lack of time and perhaps a perceived lack of applicability:

“I feel so overwhelmed by just trying to see my current number of patients and treating their known problems like diabetes and CAD that I’m not sure how I would incorporate genetic information into my current practice.”

As such, in attempting to provide sources of education for medical providers, it is important to utilize time and resources as efficiently as possible. Those responding to the survey offered clues as to how to best accomplish this. Conferences, journal articles, and newsletters appear to be the mediums with the greatest chance of reaching providers, and certain topics are more likely to draw provider attention. Cancer, developmental disabilities, and a better understanding of genetic testing appear to be on the minds of providers today. A few direct suggestions were made as to what would be useful in keeping medical providers informed about genetics. These included a regular newsletter with practical applications and educational topics, and education of providers through their professional organizations.

The Future of Genetics in Wisconsin

Medical providers in the state are largely aware of available genetic services, with a few notable gaps. However, as a population, they still have many questions about those services and about medical genetics in general. As genetics continues to move into the forefront of medicine, primary care physicians will be called upon more and more to utilize genetic knowledge in order to offer their patients the best possible care. It will be imperative for medical providers to recognize those patients who require genetic consultation or counseling, to understand the benefits and limitations of genetic testing enough to know when they themselves can order tests or when consult with a specialist is required, and to provide medical management to those patients who have been identified with a genetic condition or predisposition. Medical providers are already educating themselves and many have a firm grasp of the more significant medical genetics concepts of the day, but there is still a long way to go. Those in Wisconsin with the ability to do so must make the education of medical providers a priority in improving the quality of genetic services in the state.

Genetic service providers are a necessary and valuable asset to the medical community in Wisconsin. These providers serve thousands of patients every year for a vast array of indications. In order for the quality of service to be maintained, and the level of available service to meet demand, certain issues need to be addressed by those with the ability to do so. Medical geneticists and genetic counselors have identified those issues which strike them as the most pressing.

For one, more providers are needed. The current number of genetic service providers is simply not adequate to meet the demand for services. Providers are already practicing at or near their capacities, and claim to be under-staffed. This issue promises to become more problematic as many medical geneticists near retirement age. A serious and solution-based discussion is necessary to identify not only the causes of this shortage, but practical solutions as well. Many in the medical genetics community have suggested culprits ranging anywhere from lack of genetics training in medical schools to lack of funding for genetics positions in hospital budgets. Another potential contributor is the lack of licensure for genetic counselors in Wisconsin. As long as genetic counselors are not recognized as licensed medical professionals, it will be difficult to convince hospital administrators of the value of their services. The scope of this problem cannot be fully addressed in the limitations of this survey, but the resounding cry from the clinical genetics community is definitely, “We need more providers!”

Funding for genetic services is another issue identified by service providers. Medical genetics is not traditionally a “money-maker” for institutions and thus tends to be somewhat overlooked. This contributes to staffing shortages and has the unfortunate side effect of relegating genetics to a non-essential service, which is problematic when it comes to insurance coverage. It is impossible to ignore that genetic service providers in general report a majority of their patients having insurance of some kind, but 40% still list lack of insurance coverage as a primary barrier to adequate care. Medical providers list a lack of insurance coverage and prohibitive cost as reasons not to refer their patients to genetics, even when those services may be highly beneficial or even necessary. Insurance coverage is often denied for genetic counseling services, partly due to the fact genetic counselors are not licensed medical professionals. Coverage for genetic testing can also be denied, which may lead to substandard care or inaccurate risk or management assessments.

As Wisconsin moves into the future, it is important to ensure quality genetic services are not left behind. Providers have identified those major issues which need to be addressed immediately in

order for this to happen. While there is admittedly a bias in providers self-assessing the quality of care and needed improvements, data from this survey do seem to suggest two primary concerns: a lack of providers and a lack of funding. Focusing upon these concerns may be the best course of action for continued quality assurance in Wisconsin.