A Statewide Approach to Collaboratively Improve Access to Medical Genetics Services in Wisconsin

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ABSTRACT

Background: In the absence of a state-led initiative to monitor and address medical genetics issues affecting Wisconsin, a collaborative approach among stakeholders was implemented to identify and address service needs.

Methods: Surveys and consensus-building tools were employed to identify priority service-access needs and establish strategies to address these needs.

Results: Four statewide medical genetics priorities were identified: (1) improved coordination and collaboration, (2) increased funding for the Newborn Screening Program, (3) Medicaid policy changes regarding inpatient genomic testing and reimbursement for outpatient genetic counseling services, and (4) educational opportunities for nongenetic providers to incorporate genomic medicine into practice. Three workgroups were formed and remain active in advanced efforts in these areas.

Discussion: A stakeholder-driven process supported engagement, shared communication, and collaboration within the Wisconsin medical genetics community. Workgroups facilitated measurable progress, including increased newborn screening funding, advancement of administrative rules, expanded educational opportunities, and ongoing policy advocacy. Survey findings underscore the need for improved statewide communication and continued attention to funding and telehealth policy.

Conclusions: This initiative demonstrates an efficient and effective approach to advancing statewide collaboration and policy change in medical genetics. Sustained engagement will be critical to ensure equitable access to genetic services across Wisconsin.

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BACKGROUND

Medical genetics is a subspeciality field with an accelerating impact on patient care. In Wisconsin, the field has expanded over the past several decades to include 3 Centers for Human Genomics and Precision Medicine; expanded newborn screening; additional health care systems offering medical genetics services; multiple residency, fellowship and genetic counseling training programs; continuing education (CE) conferences; a professional genetic counselor organization (Wisconsin Genetic Counselors Association [WIGCA]); and several commercial businesses competing in the genetic testing global market.

Medical genetics knowledge, technology, and capabilities are advancing rapidly, as are public awareness and demand for genetic services, testing, and information.[1] However, acute and chronic challenges to the national and statewide genetics community continue to raise concerns regarding sustainability, widening access barriers, and inequity gaps.[2] The chronic national workforce shortage is well documented.[3,4] In Wisconsin, approximately 10 geneticists (about 5 full-time equivalents [FTEs]) serve the state, and nearly half are approaching retirement age. Workforce shortages directly affect access to care, strains training programs that rely on these professionals for education and clinical supervision, and can lead to fewer outreach clinics serving rural areas. Mitigation efforts include increasing genetic counselor capacity; implementing alternate service models, such as genetic counselor-only clinics; pairing genetic counselors with advanced practice providers for specific indications or management of established patients with known diagnoses and protocols; utilizing genetic counseling assistants and medical assistants to support administrative needs (eg, prior authorizations, genetic test coordination);[5] and educating primary and specialty providers.

The field of medical genetics straddles the public and private domains of medicine and arguably should have sustained involvement from the public sector. In 2000, the Maternal and Child Health Bureau funded a workgroup of 34 Wisconsin stakeholders (genetic and nongenetic health care professionals, state agency staff, legislators, educators, and third-party payers) to review the status of genetics in Wisconsin and develop a "Genetics Services Plan for Wisconsin" with recommendations and guidance.[6] Among its recommendations were creation of a legislatively mandated standing advisory council modeled after the Newborn Screening Advisory Group and Birth Defects Prevention and Surveillance, establishment of an autonomous state genetics program, and improvement in statewide collaboration. However, many of the recommendations did not materialize.

Table 1. Current Areas of Need in Policy, Funding, and Education (2022 and 2023)

	Funding			Policy			Education		
Issue	**2022 n=24**	**2023 n=28**		**2022 n=24**	**2023 n=28**		**2022 n=24**	**2023 n=28**	
Outpatient genetic test coverage	63%	46%	↓	75%	42%	↓	63%	42%	↓
Inpatient exome/genome	50%	38%	↓	63%	46%	↓	46%	35%	↓
GC reimbursement (public and private)	50%	38%	↓	75%	58%	↓	25%	19%	↓
Newborn Screening Program	29%	58%	↑	4%	27%	↑	21%	38%	↑
Permanent telehealth insurance coverage	54%	23%	↓	71%	62%	↓	25%	15%	↑
Capacity to address genetic return of results from research	29%	38%	↑	4%	15%	↑	21%	35%	↑

Abbreviation: GC, genetic counselor.

For this matrix question, included in the 2022 and 2023 surveys, respondents were asked to indicate the current area(s) of need (funding, policy change, or education of decision-makers) for each issue facing medical genetics service. Respondents could select as many as they thought applied.

Table 2. Current Areas of Need in Public Health, State Infrastructure, and Leadership (2022 and 2023)

	Funding			Policy			Education		
Issue	**2022 n=24**	**2023 n=28**		**2022 n=24**	**2023 n=28**		**2022 n=24**	**2023 n=28**	
Statewide genetics coordinator	33%	43%	↑	17%	14%	↓	58%	61%	↑
WI sudden unexplained death in the young	25%	25%	=	0%	4%	↑	21%	18%	↓
Newborn Screening Program	42%	57%	↑	4%	32%	↑	21%	36%	↑
Birth Defects Registry	21%	18%	↓	8%	4%	↓	21%	21%	=
Population screening for genetic conditions	42%	18%	↓	21%	11%	↓	29%	29%	=
Family advocacy and engagement	17%	21%	↑	8%	4%	↓	33%	43%	↑

Abbreviation: WI, Wisconsin.

For this matrix question, included in the 2022 and 2023 surveys, respondents were asked to indicate the current area(s) of need (funding, policy change, or collaboration) for each public health-related issue. Respondents could select as many as they thought applied.

State funding for genetics programs or initiatives has largely remained level or decreased. Until 2023, the Wisconsin newborn screening bloodspot card fee–which is used to fund the Newborn Screening Program – remained unchanged ($109/card) for more than 10 years, despite screening expansion and increased operational costs. A state genetics coordinator position was eliminated, and funding for the Genetic Systems Integration (GSI) Initiative, created to improve access to genetics services, decreased. The Health Resources and Services Administration-funded Regional Genetics Networks were defunded in 2024. Public and private payer reimbursement policies for genetic testing and services have improved over the past decade yet continue to trail advances and practice guidelines.

In the absence of a state-led initiative to monitor and address medical genetics issues affecting the entire state, from 2018 to 2020 an ad hoc professional group collaborated with Wisconsin Medicaid and several local insurers to improve access to outpatient genomic testing, including exome sequencing, considered standard of care for patients with congenital anomalies or intellectual disability.[7,8] Exome sequencing prior authorization approvals through Medicaid increased significantly–from zero to 76 during 2017-2021.[8] This successful process and outcome greatly influenced the GSI Initiative to address continuing statewide medical genetics service needs through formation of the Wisconsin Medical Genetics Stakeholder Group (WMGSG). This brief report describes the group's collaborative process and outcomes.

METHODS

Forty-eight and 52 thought leaders and stakeholders in the Wisconsin medical genetics community were invited to participate in the 2022 and 2023 WMGSG meetings, respectively. Invitees included clinical and laboratory geneticists, genetic counselors, advanced practice providers, metabolic dieticians, referring providers, administrators, and public health representatives.

The purpose of the 2022 meeting was to identify priority service-access needs within the collective sphere of influence and to establish strategies to address the needs. The 2023 meeting aimed to continue statewide communication, collaboration, and cooperation in assessing and addressing statewide needs.

Prior to both meetings, invitees completed a survey using Qualtrics Survey Software (Qualtrics, Provo, Utah). Both surveys collected respondent demographics. The 2022 survey contained additional questions in 2 domains: (1) Service Access Issues and Needs, and (2) Resources. Domain 1 categories included workforce; training programs; continuing education; policy, funding and education; and public health, state infrastructure, and leadership. Domain 2 categories included funding sources, staff, and partners. The 2023 survey contained 2 Domain 1 questions from the 2022 survey (policy, funding, and education; and public health, state infrastructure, and leadership).

Survey results were presented and discussed in facilitated, large- and small-group sessions at each meeting. Participants achieved consensus on 3 priority needs and self-selected into small groups to consider resources and strategies to address each need. This report reflects the ideas and areas of consensus documented by a dedicated notetaker. Three workgroups were established to implement strategies and effect change in each area.

Table 3. Workgroup Purposes and Outcomes (2023 to Present)

Workgroup	Strategies and Outcomes
Newborn Screening *Purpose* Develop a coordinated plan and message among stakeholders to support newborn screening funding and sustainability	*Strategy* • Facilitate statewide inter and intra institution communication regarding strategies and actions to educate legislative decision-makers on the NBSP during the 2023 biennium budget process (raising the blood spot card fee to $195) and the 2025 DHS rulemaking process (CR024-25} *Outcomes* • Contributed to a coordinated plan and message to decision-makers • Contributed to the furtherance of the rulemaking process which proposes an increase in the NBSP blood spot card fee to $223/card and the addition of two conditions to the newborn screening panel (rule modifications in Senate and Assembly committee review at the time of submission)
Policy and Advocacy *Purpose* Advocate for improved genetic testing policy for Wisconsin Medicaid beneficiaries and direct billing for genetic counseling services	*Strategies* • Identify state and federal pathways for policy change • Identify and compare genomic testing policies for regional and national large private payers and public payers *Outcomes* • Ongoing engagement with WI Medicaid to develop a genomic testing policy • WI Medicaid does not have the resources to create the enrollment pathway and define and implement covered services for GC direct billing
Workforce and Training *Purpose* Create and offer educational opportunities (with CME) for nongenetic providers to integrate genetics into their practice	*Strategy* • Work with partners to improve CME for genetics and nongenetics providers *Outcomes* • Contribution to provider training series and parent educational resources on genomic testing • Enhancement of the Genetics in Wisconsin website with more educational materials and resources

Abbreviations: NBSP, Newborn Screening Program; DHS, Department of Health Services; WI, Wisconsin; GC, genetic counselor; CME, continuing medical education.

Each workgroup consists of volunteers from multiple institutions across the state. Both authors are members of all workgroups. The lead author chairs the Newborn Screening and Workforce and Training workgroups, and the senior author chairs the Policy and Advocacy workgroup.

RESULTS

Needs and Resources Survey

The survey response rate was 52% (25/48) in 2022 and 53.8% (28/52) in 2023. Results from Domain 1 (service-access issues and needs) showed that 80% and 60% of repondents, respectively, indicated insufficient physician and genetic counselor FTEs to meet the genetic service needs in Wisconsin. Thirty-four percent and 56.5%, respectively, indicated that there are sufficient training programs for physicians and genetic counselors; however, none agreed that sufficient training programs exist for advanced practice providers. Eighty percent responded there are enough continuing education opportunities for genetic professionals, while only 16% agreed that there are enough opportunities for nongenetic providers (data not shown).

In 2022, most participants identified a need for policy change in outpatient genetic testing, inpatient exome/genome testing, reimbursement for genetic counselor outpatient services, and permanent telemedicine coverage, in addition to a need for education and funding for outpatient genetic testing (Table 1).

Several notable differences emerged between the 2022 and 2023 survey results. In 2023, the percentage of respondents indicating a need for Newborn Screening Program funding and policy changes increased, and 62% identified a need for permanent telemedicine insurance coverage – down from 71% in 2022.

In 2022, 58% respondents identified a need for statewide genetics coordination and collaboration, and 42% identified a need for additional funding for newborn screening and population screening for genetic conditions (Table 2). In 2023, respondents indicating a need for statewide collaboration and coordination remained stable.

Meeting Outcomes

Fifty-two percent of invitees attended the 2022 and 2023 WMGSG meetings (25/48 and 27/52, respectively). At the 2022 WMGSG meeting, the following priority needs were identified:

1. Statewide collaboration and coordination to address issues impacting the entire state
2. Increased funding for the Newborn Screening Program
3. Improved payer policies regarding inpatient and outpatient genetic testing and reimbursement for genetic counselor services

4. Education opportunities for nongenetic providers

Three workgroups were established: Newborn Screening, Policy and Advocacy, and Education (see Table 3 for workgroup goals and outcomes).

DISCUSSION

This brief report demonstrates an efficient approach to supporting engagement, shared communication, consensus building, and collaboration within the Wisconsin medical genetics community, with the goal of guiding and effecting positive change. The 3 workgroups established in 2022 remain active and continue to advance efforts in the prioritized areas.

The Newborn Screening workgroup facilitated statewide communication and coordinated action to educate decision-makers about newborn screening and the critical funding issues during the Wisconsin 2023 biennium budget process, resulting in an increased bloodspot card fee ($195/card). Additionally, in 2025, the workgroup supported advancement of the CR024-25, an administrative rule that raises the bloodspot card fee to $223 per card.[9]

The Workforce and Training workgroup contributed to continuing education opportunites for genetic and nongenetic providers in partnership with other educational initiatives. The Policy and Advocacy workgroup continues to engage with Wisconsin Medicaid, WIGCA, and other stakeholders to create an inpatient genomic testing policy and advocate for a genetic counselor professional fee.

Survey results demonstrated the need for improved statewide communication regarding relevant policies and issues. Most respondents indicated a need for permanent telehealth policy in 2023, even though Wisconsin transitioned to a permanent policy in 2022 that allows for reimbursement of functionally equivalent health care services provided via telehealth.[10] Additionally, the 2023 survey indicated increased concern about newborn screening funding despite state legislature approval of an increased bloodspot card fee earlier that year.

Medical genetics services, as well as existing and emerging public health programs, rely on the medical genetics community. The public sector should have a significant role in monitoring and supporting this community. Until that role is realized, identifying and addressing statewide needs will depend on grassroots collaborative approaches.

CONCLUSIONS

This collaborative initiative demonstrates that a stakeholder-driven approach can effectively identify and address critical gaps in statewide medical genetics services. Sustained engagement through workgroups has led to measurable progress in funding, policy development, and education. Continued collaboration will be essential to maintain momentum and ensure equitable access to genetic services across Wisconsin.

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