# Gillette Children's Specialty Healthcare

***A community health needs assessment***

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# Contents

# Contents (continued)

# Executive summary

Gillette Children's Specialty Healthcare (Gillette) is a not-for-profit hospital specializing in providing family-centered care for children, adolescents, and adults with disabilities or complex medical needs. Parents seek services for their children at Gillette for a variety of reasons, including diagnostic assessments, second opinions regarding specific intervention approaches, or specialty medical services that are not available locally.

In 2012, Gillette contracted with Wilder Research to conduct a regional community health needs assessment to identify opportunities to improve and expand their services to children with complex medical needs. A mixed-method assessment design included focus groups and telephone interviews with families of children with complex medical needs, interviews with referring providers, and interviews with cultural informants. In addition, interviews with representatives from non-competing hospitals similar to Gillette and a review of available literature informed study design and helped to share the key findings and issues for consideration described below.

## *Key findings*

Families who have children with special health care needs experience financial and family stress. In addition, care coordination is an unmet need for many families. Children with disabilities and complex needs, and their families, work with multiple providers and therapists, and many, especially those in greater Minnesota or out-of-state, receive care from providers in the Twin Cities or other metropolitan areas. It can be difficult for local providers to be familiar with the services and treatments children are receiving elsewhere.

Families and providers discussed challenges accessing specialty services, through Gillette and other health systems. The following identifies issues for Gillette to consider in improving communication and coordination with local medical providers:

- **Expand or enhance existing satellite clinics,** and increase the availability of traveling physicians to meet the needs of children living in communities with limited access to specialty care.

- **Identify ways to improve timely and appropriate referrals to Gillette,** by continuing to offer outreach and education to local primary care providers and pediatricians about Gillette services, and encouraging providers to empower patients and families to make their own choices about where to seek medical care. Some providers may resist referring to specialty services that are logistically more challenging for families to access, but families reported that they appreciated having all available options.

- **Facilitate communication between local providers and Gillette providers.** Referring providers requested more direct access to Gillette providers, and encouraged the use of email and other written communication between local providers and Gillette staff.

In addition to enhancing current service delivery for patients and their families, and further improving care coordination with local providers for families, the assessment identified a number of opportunities for Gillette to consider impacting broader system-level barriers that affect patient access to medical services. The following describes opportunities for consideration:

- **Explore opportunities to assist families in navigating out-of-network, or out-of-state care.** To inform efforts, Gillette should first establish the frequency with which families encounter barriers in accessing services due to Medicaid or other insurance barriers. Gillette should also develop materials to assist families in navigating Medicaid and other reimbursement challenges.

- **Work directly with state Medicaid programs and other large health systems to streamline referral and reimbursement processes**. Gillette is well-positioned to bring experience to these discussions with other states and health systems.

Based on feedback from parents who receive services from Gillette and providers who have referred their patients to Gillette, the multi-disciplinary approach Gillette uses to serve patients has many strengths and leads to high levels of satisfaction. However, parents and providers alike did identify a number of challenges families face in getting the care their child needs, and many shared ideas about ways Gillette can continue to improve the quality of services. The following identifies issues for Gillette to consider in efforts to enhance the current service delivery approaches:

- **Establish a designated care coordination role to address clearly defined barriers to care for specific patient populations.** This may include expanding services to include a defined care coordinator position, offering coordinated treatment planning meetings for families and their local health care providers, offering culturally-specific care navigators, and meaningfully supporting parents who coordinate the care for their children.

- **Increase the availability of information and accessibility of services to communities of color.** Some issues to consider include developing and sustaining relationships with culturally-specific organizations and residents, increasing the availability of resources and information in different languages, and encouraging providers to engage patients in treatment planning discussions within their cultural values and beliefs.

- **Consider the role Gillette can and should have in facilitating referrals to community-based, non-medical services and supports,** including taking a more active role in connecting families to available resources in their communities.

- **Explore opportunities to use technology to improve communication and quality of care.** This could include developing a patient and provider electronic health record portal, and creating a secure system that allows parents and local providers to share information digitally with Gillette providers.

This assessment focused on understanding the needs of children with complex medical conditions and their families from the perspectives of parents and providers. However, some of the topics raised during the assessment process are impacted by broader "upstream" factors that indirectly influence the availability and accessibility of services. While responsibility to address these issues does not fall directly upon Gillette, there may be opportunities for Gillette to support broader efforts to address these issues or work in partnership with other health care systems and state agencies:

- **Expand the health care workforce to include more providers and staff of color**, in order to continue to offer culturally-competent and sensitive care to patients and their families.

- **Identify opportunities to educate parents and community members about prevention of various chronic diseases.** Gillette could partner with local public health agencies and advocacy organizations to ensure messaging to parents and the larger community is consistent and inclusive of prevention messages regarding concussions, traumatic brain injuries, and appropriate prenatal nutrition to reduce the risk of some medical conditions.

- **Support existing early identification and intervention efforts**. This could include providing support to early childhood programs, public health nursing programs, and other in-home service providers about ways to identify children with potential complex medical conditions and provide necessary referrals.

# Project background

Gillette Children's Specialty Healthcare (Gillette) is not-for-profit hospital and clinics specializing in providing family-centered care for children, adolescents, and adults with disabilities or complex medical needs. Based in St. Paul, Minnesota, Gillette has clinics in Saint Paul, Duluth, Burnsville, Maple Grove, Minnetonka, Brainerd Lakes, and Willmar. Gillette serves a unique population of children and youth with very complex medical needs who require multi-disciplinary specialty care. The hospital's ability to provide a full range of pediatric services to meet the needs of this unique patient population draws families from across the United States, as well as internationally.

In 2012, Gillette contracted with Wilder Research to conduct a regional community health needs assessment to identify opportunities to improve and expand their services to children with complex medical needs. The assessment was developed to focus on the needs of youth in a five-state Midwest region and respond to the following research questions:

1. What are the characteristics of children served by Gillette? To what degree is Gillette serving children with complex medical conditions in the region?

2. What are the needs of children with complex medical conditions and their families? What types of service gaps exist?

3. What promising strategies can Gillette use to meet the needs of children will disabilities and complex medical conditions and improve the quality and accessibility of services they provide?

## Evaluation approach

A multi-method evaluation approach was developed to gather feedback from a variety of individuals who are familiar with the needs of youth with complex medical conditions.

### *Geographic scope of assessment*

The area of interest for the community health needs assessment included Minnesota, eastern North Dakota, eastern South Dakota, western Wisconsin, and northern and central Iowa.

### *Data collection methods*

The following data collection strategies were used in the assessment.

### Consultation with Minnesota Department of Health staff

Wilder Research met with the Minnesota Department of Health's (MDH) Children with Special Health Care Needs division to identify existing data sources to draw upon and identify any potential opportunities for collaboration.

### Literature review

Peer-reviewed journal articles were reviewed to gather background information about the most common conditions treated by specialists at Gillette and the needs of children with special health care needs.

### Key informant interviews with referring providers

Wilder Research completed interviews with 21 referring clinicians across the region.

### Telephone interviews with parents of children who receive services at Gillette

Telephone interviews were conducted with 158 parents of children who receive services from Gillette.

### Focus groups with parents of children who have complex medical conditions

Focus groups and key informant interviews were conducted with parents and caregivers of youth with complex medical conditions to identify service needs, barriers to seeking services, experiences and suggestions regarding care coordination, and the benefits and risks of telemedicine.

### Key informant interviews with Gillette staff and community representatives of cultural communities

Semi-structured key informant interviews were conducted with six Gillette staff members with interest and expertise in providing culturally appropriate health care services to patients and their families. Seven interviews were conducted with community professionals experienced in providing culturally competent services.

### Key informant interviews with non-competing clinics

Gillette identified six non-competing specialty health care centers that serve similar patient populations and provide comparable services to those provided by Gillette.

## Data analysis

Qualitative data, including key informant interview and focus group data, was analyzed using an open-coding scheme, where completed interviews and focus groups are reviewed and themes are identified and modified throughout the analysis process.

## Orientation to the report

The main body of this report describes the patient population served by Gillette and synthesizes the information collected throughout the assessment into a series of issues to consider as they develop plans to expand and enhance their ability to meet the needs of children with complex medical needs and their families. When applicable, differences across stakeholder groups (i.e., providers, parents, advocacy organizations) and regional geographic areas are identified.

# Description of Gillette patients

Gillette provides specialty health care services to children who have a number of complex medical conditions, including: brachial plexus, brain injury, cerebral palsy, craniofacial conditions (e.g., cleft lip), epilepsy, hydrocephalus, neuromuscular conditions (e.g., muscular dystrophy), orthopedic conditions (e.g., scoliosis), rheumatic conditions (e.g., juvenile arthritis), sleep disorders, spasticity, spina bifida, and spinal cord injuries.

## Characteristics of patients served by Gillette

**Most of the patients who receive services from Gillette are children, age 0-17.** Less than one-quarter of patients served (23%) are 18 years of age or older. Although two-thirds (68%) of the youth served are white, Gillette does serve a diverse patient population. In 2011, nearly 900 patients spoke a language other than English in their home.

**Gillette serves a patient population with complex medical needs.** The largest numbers of children who receive services at Gillette are diagnosed with disabilities and complex needs, such as cerebral palsy, orthopedic conditions, such as scoliosis, and epilepsy. Many of the children seen by providers at Gillette have co-morbid medical conditions that necessitate multi-disciplinary care.

**The degree to which children and families use Gillette services varies widely.** In 2011, approximately one-quarter (28%) of the children with clinical visits at Gillette (age 0-19) were seen only once. However, on average, children and their families visited Gillette six times during the year, with some children attending over 100 appointments during the past year.

# Needs of children with complex medical conditions and their families

## Brief summary of key findings

A majority of children received some of their medical services from local community providers:

- 92 percent of children saw a local community provider for at least a portion of their primary health care needs
- Fewer children received services from local community therapists (56%), specialty health care providers (32%), or mental health providers (19%)
- Many parents did indicate that they would like to receive additional services from Gillette, including vision, hearing, and psychological services, surgical procedures, and ongoing therapeutic services

Parents and providers identified several medical and non-medical services that were difficult for families to access through Gillette's primary service region:

- In many geographic areas there were shortages of pediatric specialists, especially in areas of neurology, orthopedic surgery, gastroenterology, and physical, occupational, and speech therapy services
- Non-medical supports services, such as home modification, alternative therapies, and support groups, were not available or difficult to access in many local communities
- Few clinics had care coordinators or staff who provide assistance to families beyond appointment scheduling

In addition to workforce shortages that impact the availability of services, many parents and providers described other challenges accessing services:

- State Medicaid benefit sets may not fully cover services delivered by out-of-state providers, prescribed treatments and medications, or adaptive equipment and other non-medical supports
- Out-of-network and out-of-state referrals are not readily made by all local providers

## Current use of medical and non-medical services

### Patient perspective

**Many of the families whose children are seen by specialists at Gillette also receive some of their care from local providers.** A majority of parents (92%) report their child received care from a local primary care provider during the past year, while fewer (32%) received care from a local specialist. Families who live out-of-state were less likely to see a local specialist than families in Minnesota (19%, compared to 33-35% of Minnesota families).

**Local (non-Gillette) physical, occupational, or speech therapists were used by over half (56%) of the families interviewed.** Parents reported that they saw physical, occupational, or speech therapists, other than Gillette providers because therapy is provided in their children's school or there is a therapy practice located closer to their home.

**Families from other states were also more likely to receive assistive technology services locally than those who live in Minnesota** (43%, compared to 13-16% of Minnesota residents). Both proximity to Gillette and challenges getting insurance reimbursement across state lines may be factors that contribute to these differences.

### *Non-medical services and supports*

**Families who receive services from Gillette also access a wide variety of non-medical services and supports.** Non-medical services and supports can include a number of different things, such as parent education and peer support groups, assistance with transportation, and home visiting services. Overall, about one-quarter (22%) of families who completed the telephone interview reported using non-medical services in the past 12 months.

**About one-quarter of parents would like their child or family to receive additional non-medical supports.** The most common types of services that parents were interested in receiving were tutoring services or other education support, parent and sibling support groups, summer camps, respite care, and help with transportation.

## Gaps in services for children and families

**About one in six families (15%) reported that their child was unable to access needed medical services.** The types of services families had difficulty accessing varied considerably, but included a variety of therapy services and pediatric specialists.

Although some parents identified distance and problems with insurance as barriers to accessing these services, it was more common for parents to report the services were not available in the community or at Gillette.

### *Medical needs*

#### Parent perspective

**Across all states, parents identified a need for more pediatric specialists.** Parents who participated in regional focus groups or interviews noted a number of medical needs that were unmet or challenging to accommodate, including orthopedics, neurology and other pediatric specialists.

#### Provider Perspective

**Providers identified many of the same medical needs as described by families in the focus groups.** Specifically, providers noted a lack of pediatric specialists. Providers noted that the types of specialists available at Gillette are highly-trained sub-specialties, and providers with that training are simply not available locally.

**Providers reported few pediatric orthopedists and orthopedic surgeons practicing in their regions.** While there may be local providers who work with adults, or even children with fractures, there are fewer who are experienced and comfortable working with children with complex, chronic needs. Several providers noted that offering clinic at least once per month would help to meet the needs of families locally, rather than having families travel for care.

**Another significant need identified by providers was having a local provider who is able to monitor the care of a child.** Children with complex needs work with multiple providers and therapists. It can be difficult for local providers to be familiar with the services and treatments children are receiving elsewhere.

**Similarly, providers identified a need for greater coordination of care between local providers and specialty providers**. Because the many sub-specialists who work with children with highly complex medical conditions are often not available within a single city or health care system, these children often receive services at multiple clinics and hospitals. Some providers felt that greater care coordination could reduce the total number of appointments families need to attend.

### *Non-medical supports*

**Providers also identified a number of non-medical needs for families in their respective communities, especially service coordination.** Providers acknowledge that families often receive services from many providers and therapists, and it can be difficult to coordinate that care without additional support. Providers discussed a need for care coordination for both medical and non-medical supports.

**Providers also identified a need for respite care and childcare, transportation support, and peer support groups.** The need for highly skilled respite care was especially important for parents of children who are especially fragile and require intensive, 24-hour care. Providers identified a need for more support groups and greater peer support for families with children with complex needs.

### *Barriers in accessing available services*

#### Identifying and accessing specialty medical providers

**While many parents noted that specialty medical providers may practice in their area, these specialists and providers often lack the experience and expertise to treat children with more complex conditions.** One parent noted, "We get a lot of 'we've never seen a child quite like yours.' It's disheartening." Many parents shared how they had to educate themselves about their child's conditions in order to advocate for the necessary tests and treatments for their children.

**Some families experienced challenges getting referrals to specialty providers outside their local health system.**

**Families whose children are insured through state Medicaid programs faced even greater challenges seeking specialty care from out-of-network providers.** In each of the states included in this assessment, local providers and/or parents must prove that services and care cannot be provided in-state in order for state Medicaid to cover the costs of care.

#### Impact of insurance coverage

**Few families who receive services from Gillette are uninsured.** About one-third (31%) of families who participated in the telephone interviews had public insurance coverage only for their child or children with special needs, 42 percent had private insurance only, and the remaining 26 percent had a combination of public and private insurance coverage.

In addition, about one-quarter of parents (28%) reported that their child had some kind of waiver that helps pay for services or supports.

**Although few families were uninsured, a number of families had problems getting reimbursement for services or approval for referrals to out-of-network or out-of-state providers.** More than one-quarter (28%) of families reported that their child had been denied services or supports due to their current insurance plan. Of those, families with a combination of public and private insurance were mostly likely to experience denials (39%). In addition, 29 percent with public insurance only experienced denials, as did 20 percent of families with private insurance only. Families out-of-state on public insurance only were among the most likely to experience denials (43%).

## Referral to specialty services

### *Patient perspective*

**Many families are referred to specialty care providers through medical professionals such as pediatricians/family practitioners, physical therapists, or other specialists, such as neurologists.** In addition, families connect to specialists through individual, on-line research regarding healthcare systems and providers' expertise, connections to other parents with children with special needs, and advocacy organizations, such as Family Voices.

**Most families who completed the telephone interview did not have any problems receiving the initial referral to Gillette**. There was not significant variation among families based on geographic region. However, some families who had received services at Gillette and other healthcare systems initially experienced barriers to accessing specialty care for their children. Some parents reported difficulty accessing providers when local providers refused to make an out-of-state referral.

**Most parents felt that their child's primary care physician almost always met their child's medical needs and made appropriate referrals**. This was true among parents from the Twin Cities metro (86%), greater Minnesota (86%), and out-of-state (91%). However, some out-of-state families (10%) felt that their child's primary care physician almost never meets his/her medical needs or makes appropriate referrals.

**Almost one-third of parents indicated that they would like their child to receive more services at Gillette.** Parents living in the Twin Cities metro (38%) were more likely to agree that they would like their child to receive more services at Gillette compared to parents in greater Minnesota (28%) and out-of-state (24%) (Figure A16). When asked what specific services they want their child to receive, parents listed a variety of options, including: vision services, hearing services, psychological services, additional surgical procedures, physical and occupational therapy, and pain management.

Parents also shared that they trust Gillette providers' knowledge/expertise and that additional services would strengthen their child's continuity of care at Gillette. Parents who live outside of Minnesota suggested that Gillette providers periodically visit their cities or have an outreach clinic to assist with orthopedics and provide assistance to access, fit, and repair durable medical equipment.

**Provider perspective**

**Most providers learned about Gillette's services word-of-mouth via their colleagues' recommendations, or they followed the referral pattern of the healthcare system in which they worked.** Some providers learned about Gillette through educational conferences sponsored by Gillette, marketing materials, spending time at Gillette during their medical training, or by searching for a specific specialty such as pediatric neurology.

Many providers indicated that they determined that Gillette was an appropriate referral based on the expertise, knowledge, and experience of the Gillette providers. Providers referenced Gillette's orthopedic, neurology, and rehabilitation medicine departments as some of the strongest in the region. Providers also highlighted Gillette's reliable communication and coordination of care. Several providers remarked about the ease of accessing Gillette providers, receiving their notes in a timely manner, and being impressed by how well the various providers work with one another.

# Potential strategies to improve patient care

While the purpose of this report is to identify opportunities to improve and expand services, it is important to note that the parents of Gillette patients who participated in telephone interviews tend to be very satisfied with the services they have received. When asked to identify the most important thing Gillette could to do help their child be as healthy as possible, most parents felt that Gillette simply needed to continue providing the same types of high-quality services.

Multiple strategies can be used to address gaps in services and meet the needs of patients. As part of the assessment, three strategies of interest to Gillette staff were explored: care coordination services, telehealth models, and strategies for providing culturally appropriate care.

## Communication between providers

Both care coordination and telehealth models are strategies that can be used to not only meet the needs of patients, but to improve communication between providers. Among both parents and providers, most were pleased with the frequency of communication between Gillette and local providers. However, there were some concerns about the timeliness of communication and interest in more email or telephone interaction, rather than only the sharing of written visit summaries.

### Parent perspectives

**Overall, a majority of parents feel that Gillette providers regularly communicate with their local medical providers.** Eighty-six percent of parents reported that Gillette providers communicated with their local providers "almost always" or "most of the time."

### Provider perspectives

**Although most providers received, and were generally pleased with, the written documentation they received from Gillette, the degree to which providers were able to communicate more directly with Gillette providers through email or via telephone varied**.

## Care coordination

### *Key findings*

**Care coordination was described in many different ways by both parents and providers.** While some parents considered care coordination simply as the assistance they received scheduling appointments with multiple providers, other parents and providers described care coordination as improved communication between providers. Fewer parents and providers described care coordination as the support families receive to identify additional medical and non-medical service needs in the community or the role others may play in helping parents address insurance barriers or otherwise advocate for needed services.

**While the timely sharing of written visit summaries and other documentation with referring providers appears to be one of Gillette's strengths, there are opportunities to enhance and expand care coordination activities to better meet the needs of children and their families.** Gillette staff regularly work with parents to schedule same-day appointments when multiple providers must be seen and providers often send written materials to the child's referring physician to summarize what occurred during the visit and any planned next steps. To some degree, these patient-centered practice strategies do provide families with better coordinated services. While generally satisfied with communication between Gillette and local providers, parents and providers alike identified a number of ways care coordination efforts could be improved.

#### Parent perspectives

**Few of the families served by Gillette receive any care coordination beyond assistance in scheduling appointments.** One-third of the parents (33%) whose child receives services from Gillette reported getting some help arranging or coordinating their child's care among the different doctors or services he or she uses. Of the parents who receive care coordination services, a majority (77%) report that support comes from Gillette staff, often identifying appointment schedulers, nurses, or providers, as the individuals who provide this additional help. When asked to describe the type of care coordination services they receive from Gillette, most parents described support in scheduling appointments, while others brought up communication between providers or aspects of patient-driven care, such as providers extending the length of the appointment when needed.

**For some families, care coordination is an unmet need.** One-fifth of parents reported that they could have used additional help arranging or coordinating care during the past 12 months.

**Parents often saw themselves as their child's primary care coordinator.** Parents typically reported that they saw themselves as the care coordinator for their child, often bringing binders of information to all of their child's appointments.

**Parents want care coordinators with expertise to help improve communication between providers.** Parents want to work with staff who not only understood their child's diagnoses and needs, but who were also aware of resources available in their community and able to help parents access necessary services and resources.

**Provider perspectives**

**Although most providers were generally pleased with the level of communication they received from Gillette providers, some communication delays or difficulties talking directly to the provider were considered barriers to care coordination.** With few exceptions, referring providers felt that they received written documentation (i.e., visit summaries or treatment notes) in a timely manner from Gillette. However, some providers had difficulty contacting the Gillette provider if they had additional questions about the child's treatment plan.

**Limited funding and staffing challenges can be barriers to implementing comprehensive care coordination models.** Funding was identified as a barrier to enhanced care coordination services by many clinic representatives and providers. Minnesota's health care home model offers some reimbursement incentives for clinics and hospitals to adopt care coordination practices. However, it was outside the scope of this assessment to determine the financial feasibility of adopting any potential care coordination models.

## Telemedicine

Telemedicine describes a number of strategies, including videoconferencing, transmission of video and still images, remote monitoring of patient vital signs, and electronic patient portals, that are used to exchange medical information across sites in order to improve patients' health. Gillette defines telemedicine as a provider providing services to a patient in a clinic or hospital setting; telehealth refers to in-home medical visits between providers and patients/families. Both telemedicine and telehealth are becoming increasingly common in managing patient care (American Telemedicine Association, 2007).

Videoconferencing, a key telehealth strategy, is used often to improve communication between specialists and primary care providers. It can allow providers to work more collaboratively across distances and reduce time and travel for families who need specialty care that is not readily available within their region.

### *Summary of key findings*

Although very few parents have experience using telemedicine services, some did think telemedicine could be a helpful way to communicate with medical providers for certain types of appointments. Parents, particularly those who lived farther away from Gillette, thought telemedicine could be used effectively for consultation services and brief follow-up appointments.

**Parent perspectives**

**Although parents did not want to see telehealth replace their usual type of care, some were interested in using technology to receive consultation or services for non-emergency issues**. For families who lived farther away from Gillette, some felt telehealth could be an appealing option for determining whether an appointment at Gillette was needed or for brief visits, such as dietary consultations, requests for medication refill, or review of test results.

**Some parents also felt telemedicine might be a useful tool in improving communication between providers.** Parents who participated in the focus groups also felt that providers could use telemedicine to consult with one another about the child's care.

## Culturally competent care

Gillette serves a diverse patient population from cultures that have different values and beliefs around health and health care services. In 2011, 68 percent of patients who received services at Gillette were white, while fewer identified as black (African-American or African-born) (6%), Asian (3%), Hispanic (2%), or American Indian (1%). The race/ethnicity for a number of patients was not known (14%) or identified as other (7%). Although a relatively small percentage of Gillette patients speak languages other than English overall, Gillette served nearly 900 patients who spoke 44 different languages in 2011.

Given the current diversity of Gillette's patient population and anticipated growth in diversity among Minnesota residents and throughout the county, there is a need to continue to improve and enhance the ways that culturally competent health care services are provided.

The following highlights promising practices in expanding culturally competent service delivery.

**Take deliberate steps to ensure patients and families understand and can implement the recommendations given by providers.**

**Develop or enhance partnerships with community based organizations and providers.**

**Use a variety of approaches to gather verbal feedback from patients and families.**

# Issues for consideration

The results from this community health needs assessment can be used to prioritize the most pressing needs of families and consider ways in which Gillette can best address these needs.

The assessment findings identified a number of key areas that Gillette staff will consider addressing in order to improve the accessibility and quality of their services and address some of the most pervasive barriers families face when they have a child with complex medical conditions.

## Opportunities to improve communication and coordination with local medical providers

**Identify ways to improve timely and appropriate referrals to Gillette.** Parents discussed challenges getting connected to appropriate services and noted that, because of the lack of expertise among local providers, parents themselves often research potential diagnostic tests, therapies, and treatments for their children's conditions.

**Continue to provide outreach and education to local primary care providers and pediatricians, as well as local specialists**. In particular, Gillette should focus outreach efforts on earlier identification of patients who may require specialty services.

**Educate providers to empower patients and families to make their own choices about medical care.**

**Continue to promote the variety of services available through Gillette to parents and referring providers.**

**Consider opportunities to expand or enhance existing satellite clinics**. Specifically, providers noted that additional clinics with pediatric orthopedic surgeons, and pediatric neurologists, would help meet the needs of patients who live outside the Twin Cities metro area.

**Expand number and location of satellite clinics.** Gillette should assess the extent to which the current satellite and outreach clinics are meeting the needs of families in greater Minnesota. The expansion of satellite clinics to locations in surrounding states could also help meet the needs of children with complex medical conditions.

**Increase the use of traveling physicians to meet needs of children living in communities with limited access to specialty providers.** This could be done through in-person clinics, or through the use of telemedicine and consultation between Gillette specialists and local providers.

**Facilitate communication between local providers and Gillette providers**. Although many referring providers felt that they received timely written information from Gillette, some wanted more telephone communication and consultation from Gillette to ensure continuity of patient care.

**Encourage use of email and other written communication between Gillette providers and local providers.** Several local providers expressed great satisfaction with those Gillette providers who are accessible via email. Providers noted that not all questions are urgent, and it would be helpful to have email communication as an option for coordinating care for patients in less urgent scenarios.

## Opportunities to enhance current service-delivery approaches

Based on the feedback from parents who receive services from Gillette and providers who have referred their patients to Gillette, the multi-disciplinary approach used by Gillette to serve patients has many strengths and leads to high levels of satisfaction. However, parents and providers alike did identify a number of challenges families face in getting the care their child needs, and many shared ideas about ways Gillette can continue to improve the quality of services.

**Establish a designated care coordination role to address clearly defined barriers to care for specific patient populations.**

**Increase the availability of information and accessibility of services to communities of color.** The way complex medical conditions are understood can vary considerably across different cultural communities. In addition, language barriers can pose significant challenges to providing appropriate care. Although Gillette has interpreters available to families during appointments and is working on an ongoing basis to provide culturally competent care, a number of potential strategies to better address the needs of patients of different culturally communities came out of conversations with Gillette staff and representatives of different cultural communities:

**Develop and sustain relationships with culturally-specific organizations and residents.**

**Increase the availability of resources and information in different languages.**

**Encourage providers to engage patients in discussions around their cultural values and beliefs.**

**Consider the role Gillette can and should have in facilitating referrals to community-based, non-medical services and supports.**

**Explore opportunities to use technology to improve communication and quality of care.** Although parents did not want telehealth services to replace face-to-face appointments with their child's provider, many felt that videoconferencing or other telehealth approaches could reduce the number of appointments and could enhance their child's quality of care..

**Develop a patient and provider electronic health record portal.**

**Create a secure system that allows parents and providers to share information digitally with Gillette providers.**

## Addressing broader system-level barriers that impact access to medical services

Families and providers who participated in this assessment continually discussed challenges with accessing needed medical care out-of-network, or out-of-state. While Gillette may not be positioned to affect these challenges directly, there are strategies Gillette could employ to help facilitate families getting access to Gillette.

**Establish the scope of the problem.** Gillette should consider systematically collecting information from patients about the extent to which they experienced difficulties in accessing Gillette due to Medicaid challenges, to determine how best to approach further collaboration with state Medicaid offices or support families in navigating the process.

**Develop materials to support patients and providers in navigating Medicaid reimbursement.**

**Consider working directly with state Medicaid programs to understand processes and possibly streamline approvals.**

**Explore barriers to referring out-of-network for large health systems in surrounding states.**

## Looking further upstream

This assessment focused on understanding the needs of children with complex medical conditions and their families from the perspectives of parents and providers. However, some of the topics raised during the assessment process are impacted by broader "upstream" factors that indirectly influence the availability and accessibility of services. While responsibility to address these issues does not fall directly upon Gillette, there may be opportunities for Gillette to support broader efforts to address these issues or work in partnership with other health care systems and state agencies:

**Expand the health care workforce to include more providers and staff of color.**

**Identify opportunities to educate parents and community members about prevention of various chronic diseases.**

**Support existing early identification and intervention efforts**. Gillette could consider ways to support existing early childhood screening programs administered by state agencies or to provide training and education to primary care providers, public health nurses, and other in-home service providers about ways to identify children with potential complex medical conditions and refer them for further assessments.

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