



**Gillette
Children's**

Specialty Healthcare



2019

COMMUNITY

HEALTH

NEEDS

ASSESSMENT

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ACKNOWLEDGMENTS

We extend our thanks to the caregivers, providers, and community partners who shared their perspectives on the needs of children with complex medical needs and their families.

Community partners

The following community partner organizations provided key insights into the needs of children with medical complexity, as well as the organizations and systems that serve them and the communities in which they live. These organizations include: ChildServe, ACR Homes, Regions Hospital, Pediatric Home Services, Minnesota Council on Disability, Saint Paul Public Schools, Minnesota Department of Human Services, Pediatric Therapy Services, Lifescape Children’s Services and Mankato Clinic.

Gillette staff

We want to acknowledge the staff from Gillette Children’s Specialty Healthcare who worked closely with us to design and implement this community health needs assessment. Staff participated in interviews, coordinated with community partners, shaped the assessment design and provided data and insight about Gillette’s patient population and services.

Wilder Research

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CHNA BACKGROUND

Through the Affordable Care Act (ACA), all not-for-profit hospitals are federally required to conduct a community health needs assessment (CHNA) that identifies the health needs and priorities of the community it serves and the steps the hospital will take to address these issues. This report describes the community served by Gillette Children's Specialty Healthcare and the process used to conduct the assessment, identifies prioritized and non-prioritized health issues, and summarizes resources available to address these needs. The report also highlights work completed by Gillette to address needs that emerged during its 2016 CHNA. Gillette will use information from this assessment to develop an implementation plan to respond to the prioritized health issues within the community it serves.

ABOUT GILLETTE CHILDREN'S SPECIALTY HEALTHCARE

Gillette is a not-for-profit hospital and group of clinics specializing in family-centered care for children and adolescents with complex medical needs and disabilities. Gillette also provides core services to limited populations of adults with childhood-onset disabilities. Some of Gillette's specialty areas include pediatric orthopedics, neurology, neurosurgery, physical medicine and rehabilitation, and complex pediatrics. 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 and surgical services that are not available close to their home. Based in Saint Paul, Minnesota, Gillette has clinics in communities located across Minnesota. The hospital also draws families from across the United States and internationally.

Metro locations: St. Paul Campus, Burnsville, Maple Grove, Minnetonka and Phalen
Greater Minnesota locations: Alexandria, Baxter, Bemidji, Duluth, Mankato, Marshall, St. Cloud and Willmar

Description of the community served by Gillette

The national Maternal and Child Health Bureau defines children with special health care needs as those who are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who require additional health care and health-related services. Those children with special health needs that are the most medically fragile and have the most significant medical needs are termed *medically complex* (Cohen et al., 2011).

Nationally, it is estimated that children with special health needs make up 14% of the population; however, if we only consider the most medically complex children, estimates are closer to 4%. Minnesota-specific population estimates of medically complex children are not available; however, if we assume 4% of children in Minnesota were medically complex that would equate to nearly 52,000 children.¹ While the population of medically complex children is small, the number of children with complex medical

¹ Based on 2017 American Community Survey Minnesota population estimates.

needs is expected to rise as medical advances improve survival rates for infants born prematurely and children with severe chronic conditions (Cohen et al., 2011).

For the purposes of this assessment, the community served by Gillette is defined as children, teens, and to a limited extent, adults living throughout Minnesota or surrounding states who are medically complex due to having conditions requiring specialty medical, rehabilitation and surgical services.² This community definition was developed by examining existing data on children with medical complexity, as well as reviewing information about Gillette's current patient population.

Gillette also serves populations that are medically underserved, such as those impacted by health disparities and those at risk of receiving inadequate care due to geographic, language, financial, or other barriers.³ Wilder Research took additional steps with the design and implementation of data collection to ensure perspectives from medically underserved populations were adequately represented in this CHNA. These steps include:

- Oversampling the following groups in the caregiver interview sample: those living in greater Minnesota, those with higher medical needs and persons of color.
- Providing the option for the caregiver interview to be done in Spanish or Hmong.
- Interviewing organizations that serve populations from a variety of cultural and geographic locations.

Gillette patient data

Gillette serves a variety of populations, but the majority of their patient population is white, non-Hispanic and English-speaking. While Gillette's focus is on serving children aged 0-17, 19% of their patient population is aged 18 or older. Slightly more than half of patients live in the seven-county Twin Cities metro, with the remainder coming from Greater Minnesota, a state other than Minnesota or another country (Figure 1).

Gillette serves patients with a wide variety of complex, co-occurring disorders, with the most common individual diagnoses being cerebral palsy, scoliosis, craniosynostosis/plagiocephaly/torticollis, and epilepsy/seizures (Figure 2). Given the ages of patients seen at Gillette, it is not surprising that 66% of current patients first utilized Gillette no more than five years ago. While patients may have more than one payer, it is most common for their primary payer to be a commercial payer (59%) or Medicaid (31%) (Figure 3).

² Adults who started at Gillette as children would also be included in the population, but Gillette does not focus care on adults.

³ <https://www.irs.gov/charities-non-profits/community-health-needs-assessment-for-charitable-hospital-organizations-section-501r3>

Table 1. Demographics of patients served by Gillette

Race (N=23,355)	N	%
White	17,134	73%
Black/African American	1,748	7%
Asian	909	4%
American Indian/Alaska Native	223	1%
Other	38	0%
Unknown	3,303	14%
Ethnicity (N=23,355)	N	%
Hispanic or Latino	1,556	7%
Not Hispanic or Latino	20,963	90%
Unknown	836	4%
Language (N=23,264)	N	%
English	22,227	95%
Spanish	431	2%
Somali	358	2%
Other	248	1%
Unknown	91	<1%
Age (N=23,355)	N	%
Age 5 and under	7,638	33%
Age 6-17	11,269	48%
Age 18-25	1,926	8%
Age 26+	2,522	11%
Geographic region (N=23,355)	N	%
Twin Cities metro	13,614	58%
Greater Minnesota	7,254	31%
Five-state region	2,137	9%
Out of state	308	1%
International	22	<1%
Unknown	20	<1%

Gillette Children's Patient Geography – Unique Patients by State



- Greater than 20,000 patients (Minnesota)
- Greater than 1,000 patients (Wisconsin)
- Greater than 100 patients (Iowa, North Dakota, South Dakota)
- Greater than 25 patients (Nebraska, Illinois, Texas, Michigan)
- 1 or more patients

Table 2. Most common diagnoses

Diagnosis (N=15,213)	N	%
Cerebral palsy	4,597	30%
Scoliosis	4,201	28%
Craniosynostosis, plagiocephaly and torticollis	2,774	18%
Epilepsy and seizures	2,530	17%
Spina bifida	563	4%
Muscular dystrophy	548	4%

Table 3. Patient access and utilization

Time since first patient visit (N=23,355)	N	%
Less than 1 year	2,640	11%
1 through 5 years	12,899	55%
6 through 9 years	2,900	12%
10+ years	4,916	21%
Primary payer (N=23,355)	N	%
Commercial	13,787	59%
Medicaid – Minnesota	7,321	31%
Medicare	1,253	5%
Self-pay	461	2%
Other payer	298	1%
Other government	235	1%
Average outpatient physician visits (N=23,355)	N	%
Average total visits per month, all patients	4,148	-
Average visits per patient per year	2.13	-

ASSESSMENT APPROACH

In 2019, Gillette contracted with Wilder Research to conduct a regional community health needs assessment to identify opportunities to improve and expand their services to children, teens and select adults with complex medical needs. In 2016, Gillette focused their CHNA efforts on the needs of children and families in Minnesota because most families they serve fall into this geography, and it would provide an opportunity to identify needs and implementation strategies within a small scope (state-level versus regional). However, after three years of diligent efforts to address the 2016 priority needs (care coordination, caregiver support and access to care and treatment) and an organizational vision to connect with and serve more children and families throughout the region, Gillette decided to expand the scope of their CHNA in two ways:

- Focus on gathering feedback from parents and community stakeholders in and outside of Minnesota
- Build upon Gillette's understanding of the needs identified in 2016 by asking additional, broader questions to identify emerging needs, additional nuances surrounding existing needs and thoughts about addressing needs

The following questions guided the assessment process:

- What are the characteristics of children Gillette currently serves?
- What are the biggest needs of families with medically complex children?
- What challenges do families experience in accessing services at Gillette?
- What services and supports outside of Gillette are missing or inaccessible to families?
- What support can Gillette provide to help families coordinate care and treatment?
- What support can Gillette provide in providing or referring families to community services?

Data collection methods

To develop the most complete picture of the needs of children with medical complexity and their families, Wilder utilized a multimethod approach to gather information from families who have children with medical complexity (or adult patients), community partner organizations that serve or support these children and their families, and Gillette staff who manage the systems that serve these patients and families or who directly serve patients themselves. The following describes each of the data collection strategies used throughout the assessment.

Literature review. Background information, including peer-reviewed journal articles, gray literature and secondary data sources such as data from the Minnesota Department of Health, were reviewed to build a description of the overall population of children with special health and complex medical needs, as well to as understand these needs and how this group may change.

Telephone and online survey of caregivers of children receiving services at Gillette or adult patients at Gillette. Gillette staff compiled a list of all patients who received services in the past year, including demographic data, summary information about care received and contact information for caregivers. Patients who chose to be excluded from data collection efforts were not included. All records with an email address received an email inviting them to take the survey online, while a Wilder Research interviewer called those without an email and asked them to complete the survey over the phone. The sample of respondents was drawn to ensure a diversity of respondents, based upon whether or not they were part of the Complex Care Clinic; their location (Greater Minneapolis-Saint Paul metropolitan area, Greater Minnesota and states outside of Minnesota); and their identified race and/or ethnicity. Patients identifying as persons of color, those with more complex needs and those living outside metropolitan area were oversampled to improve the likelihood of identifying any nuances that exist among those communities. A total of 202 surveys were completed. Caregivers were asked to reflect the needs of their children and family related to medical care, community services and anything else in their life that impacts those areas. They were also asked to discuss their experiences accessing and receiving services at Gillette, the strengths and resources they utilize as caregivers and suggestions for improving the systems that serve their family.

Table 4. Characteristics of caregiver interview respondents (N=202)

Patient of the Complex Care Clinic	N	%
Yes	56	28%
No	146	72%
Race	N	%
White	155	77%
Person of color	37	18%
Unknown or answer left blank	10	5%
Location of patient	N	%
Twin Cities metro	113	56%
Greater Minnesota	61	30%
State other than Minnesota	28	14%
Respondent's relationship to patient	N	%
Parent	186	92%
Other family member	7	3%
Self – young adult patient	9	5%

Key informant telephone interviews with community partner organizations. Gillette staff, with the assistance of Wilder Research, identified 11 persons at organizations that serve or support children with complex medical needs and their families who could provide key insights. Community partners represent a variety of perspectives, including public health, human services, rural health care providers, urban health care providers, advocacy organizations, home- and community-based service providers and schools. Partner organizations were asked to describe what they felt were the biggest areas of need for children with medical complexity and their families broadly and in the existing areas of concern (care coordination, access to services and caregiver supports). Stakeholders were asked to describe what efforts should be started, improved or continued to better meet the needs of families, as well as how they could better partner with Gillette in those efforts.

Key informant telephone interviews with Gillette staff. Gillette staff identified 20 key individuals who would provide a variety of insights into the needs of patients and families and the role of Gillette in their care. Interviewees included urban providers, rural providers, nurses and nurse practitioners, social work staff and managers of areas such as finance, assistive technology, human resources, operations and telemedicine. Gillette staff were asked to describe what they felt were the biggest areas of need for children with medical complexity and their families broadly and in the existing areas of concern (care coordination, access to services and caregiver supports). Using their knowledge of Gillette, they were asked to reflect on what could be changed inside and outside the Gillette system to better serve families.

Data analysis

Qualitative data from key informant interviews and surveys were coded and analyzed using ATLAS.ti and Microsoft Excel. Themes were identified and modified throughout the analysis processes. For quantitative survey data, basic descriptive analysis and cross-tabs were run using SPSS. Illustrative quotes from the interviews are used throughout the report to provide more insight into the experiences of children and families.

HEALTH ISSUES IDENTIFIED IN 2019

The following health issues identified through Gillette's 2019 Community Health Needs Assessment, are separated into priority and non-priority categories. Priority health issues were identified through a prioritization process among Gillette staff, with support from Wilder Research. Given the complex, interconnected nature of care received by these children and families, there is some overlap in the health issues identified. While the interaction between these different issues will be considered as Gillette moves forward with addressing the issues facing children and families, for the purposes of this assessment, each issue is discussed as a distinct topic.

Priority health issues

Accessing Gillette medical care and treatment can be burdensome

Overall, patients and caregivers utilizing Gillette services are very satisfied with the care they receive and the providers they work with; however, caregivers and a number of Gillette staff members acknowledged there are still challenges that impact families' ability to access the services they need at Gillette without considerable effort and time.

- **Difficulty scheduling appointments.** Caregivers and staff reported that scheduling appointments at Gillette could be very time-consuming and challenging. This seemed to be especially true if the steps needed to make an appointment (having an appointment order from staff, calling the correct person at Gillette to make the appointment, etc.) were not followed in the exact order or in a timely enough manner. This could be the result of issues such as families not calling to schedule shortly after an appointment order is provided or Gillette staff not following up with families soon enough.
- **Limited appointment availability.** Caregivers experienced difficulty getting appointments in a timely manner (i.e., they were unable to get an appointment when they felt it was needed) and getting appointments that were not overly burdensome on their schedule or the schedule of the patient. Caregivers seemed particularly concerned about the amount of school children may miss for regularly scheduled appointments during the school day.

Caregivers most concerned were those...

- not part of the Complex Care Clinic
- living in the metro area

70% of Gillette staff respondents identified appointment scheduling as an issue that hinders access to services.

- **Inconsistent access to coordinated appointments.** While patients who are part of the Complex Care Clinic get additional support in coordinating appointments, those patients needing multiple appointments who are not part of that clinic struggled to get the appointments set up in a way that was most efficient for their time.

The following are caregiver quotes exemplifying this health issue:

I can't get appointments in a timely manner. I have to make them about six to eight months out. It's hard to get them scheduled and hard to call them.

I have had a lot of issues with appointments. No call backs, no orders are made for the next appointments, and there is no communication to the doctors from appointment setters or vice versa from the doctors to the scheduling team.

I never get to meet with my daughter's doctors in one day. If I have a question with one doctor and they need to consult with another doctor... I may have to wait a month or more to hear back since appointments are months apart.

A lack of robust, proactive care coordination

All respondents acknowledged that the current maze of systems for meeting the needs of children with complex medical needs and their families creates significant care coordination challenges for families and an opportunity for providers to do more to reduce this burden.

- **Gillette staff may not have the time and resources to effectively communicate with other internal or external providers or staff, which can create greater coordination burden on families.** Successful care coordination requires good communication and time. In order to lessen the burden on families, Gillette staff need time to establish good rapport and communication with other providers or staff to ensure successful sharing and use of information critical to good coordination. Because families highly value Gillette providers, families often feel Gillette staff are best positioned to inform all other providers or services the patient interacts with or receives services from.

Nearly all caregivers felt their local primary care, urgent care or emergency providers could benefit from communicating with Gillette and that it would improve care for their child.

However, when caregivers need to reach out to other providers (within or outside Gillette), it is critical that they know exactly who to contact and have an expectation of a timely response.

■ **The lack of a central staff person(s) with a comprehensive understanding of a patient and how to meet their needs places excess burden on caregivers.**

Respondents from all backgrounds felt the onus is on caregivers to determine patient needs in order to ask for services. Ideally, a staff person would know the patient's needs well enough to proactively identify and address them or support caregivers in meeting them. Given the complexity of patient needs and the systems that serve them, this is a huge burden on caregivers. This challenge, and the value of having a key central contact, would likely be most evident during times when caregivers identify an increase in burden or uncertainty with their child's care, such as during a new or changed diagnosis, aging into different services or transiting home from an inpatient stay.

■ **Technology limitations hinder information sharing.**

While in-person or phone communication is still important, many respondents reported that limitations on sharing records and patient information results in additional burden on families. Respondents reported the lack of digital information sharing results in families having to fill out similar forms many times, families having to self-report medical information with each new provider and an increased likelihood that not all staff or providers have a complete understanding of the patient's current needs and services received.

65% of Gillette staff respondents identified sharing patient records as an issue that hinders access to the effective coordination of care.

■ **Patient and family choice needs to be clear.** Community stakeholders and caregivers felt patients and families need to understand their rights as well as service and treatment options, and need to ensure they are able to make the best choice for them and their family. Patients and families also need to know what to expect from every system they interact with to help set appropriate expectations and understand when things are not working appropriately.

The following are caregiver quotes exemplifying this health issue:

Right now we have to go to other clinics for primary care, and there's a disconnect between those providers and his Gillette providers (who we prefer). The other clinics don't know him and I guess Gillette hasn't been able to share enough information to ease that yet.

We notice that we had to advocate for many things ourselves. There was not communication within themselves, we had to seek out other families going through the same thing and that's what got us through this process. Gillette was more reactive, than proactive.

Inadequate connections to supportive community resources and education

While having access to specialty health care providers such as Gillette is critical to the health of medically complex children, having services and resources within these patients' communities is just as important to ensure the best possible quality of life.

- **Families often rely heavily on home- and community-based services, yet struggle to navigate finding and obtaining them.** Families struggle to learn about and determine their eligibility for county-based waived services because of differences across counties, large amounts of paperwork and challenges connecting with staff who can provide correct information. Additionally, it often takes families a considerable amount of research to find organizations that can provide the services their children need, where they need them.
- **Caregivers and stakeholders have difficulty obtaining and maintaining appropriate assistive/adaptive equipment and technology.** Caregivers and community stakeholders both identified this as a challenge for children with medical complexity. At the outset, it is difficult for families to access this equipment because of a lack of vendors in their area, an inadequate selection of products, nonresponsive vendors and/or a lengthy process. In the long term, caregivers and patients face challenges ensuring that equipment is properly maintained and/or adjusted for fit and is replaced as needed because of growth or changing medical needs.

The biggest concern of 16% of caregivers was obtaining and maintaining appropriate equipment.
- **Parents have limited opportunity to participate in recreational activities.** Caregivers expressed a need for patients to participate in recreational and/or therapeutic activities such as art, music or sports. Caregivers want activities that are appropriate for patients' needs, but not necessarily provided in a way that always separates medically complex children from their noncomplex peers.

Half of caregivers said their child had an unmet need for therapeutic or appropriate recreational activities.
- **Support specifically for caregivers and families is still lacking.** Respondents from all perspectives acknowledged there remained a large need to better connect caregivers and families of children with complex medical needs. There is a desire for not only online interactions but also in-person support. Caregivers particularly felt it is left to them to organize these groups, but this task of connecting many different families might be better addressed by those with a larger network, such as Gillette. Half of Gillette respondents identified the need for peer support among caregivers. Beyond peer support, some community stakeholders (40%) and Gillette respondents (25%) also felt that mental health services would benefit caregivers.

- **Patient and family needs increase during a first diagnosis, during a significant change in a patient's health status, or when patients transition home after receiving care in a longer-term, inpatient setting.** During these times, families often struggle with understanding how the diagnosis presents, what it may effect, treatment options and how to discuss the diagnosis with others. Caregivers also often felt ill-equipped to administer new medications or provide care they were not familiar with, especially if they are only provided information without supervised, hands-on practice. Additionally, once patients are living at home, caregivers felt they had limited ongoing support to access the home- and community-based services so critical to ensuring the patient can remain there.

Caregivers most concerned were those:

- in the Complex Care Clinic
- living in rural areas

50% of Gillette respondents identified caregiver and family education as a significant health issue during transitions.

The following are caregiver quotes exemplifying this health issue:

Gillette should have a community resource person to just educate you a little bit more about what kinds of resources or options are out there for you and your family and your child... there isn't really anyone to tell you, "These might be the issues you face as you leave Gillette and transition to home and if you have issues with A,B,C,D, and these are the places you can go to for help."

It would be great for a provider or someone else to create an in-person parent group and have that support. But it's always the parents that want the group so the parents are the ones who have to lead the groups. They're supposed to be in the group, not to lead or create the support for others.

Gillette has the cerebral palsy road map which is a start, but it would be great to put something together on specifics about your child's classification and the way it is manifested. Then do that for other conditions as well.

Lack of financial support and advocacy

A family's financial means is at the core of their access to and utilization of services. National studies show the care required by these children is extremely expensive, regardless of the payment source; some Medicaid estimates indicate this population represents 6% of all children on Medicaid, but accounts for more than 40% of total Medicaid spending on children (Pediatric Complex Care Association, 2016). It is also apparent that the cost of care and financial strain of having a medically complex child fall largely on the family. Nationally, more than half of these families reported experiencing financial hardship or had a family member end their employment to care for the child (Kuo, Cohen, Agrawal, Berry, & Casey, 2011).

■ **Managing finances is a daily stress.** Many families are likely ill-prepared to handle all the short- and long-term financial implications of having a child with medical complexity. These children often need services and equipment that are not only expensive to pay for but may also have an opportunity cost for families. These things may include: major surgery, therapeutic services, assistive technology, home modifications, prescriptions, alternative forms of transportation, alternative forms of recreation, around-the-clock care and a parent taking temporary or permanent leave from their employment.

25% of Gillette staff respondents felt families need help understanding the financial implications of their child's care needs.

■ **Accessing state or county benefits, as well as navigating insurance, has a significant impact on a family's finances.** While all families must deal with financial stress, families with medically complex children must often navigate complex financial decisions around state and county benefits (e.g., waivers), private insurance or paying for care out of pocket. A family's finances, which includes both what they can afford and the value of their assets, directly influence what services they can qualify for and receive and how they are paid. Unfortunately, for many families, it is very difficult to determine a balance between allowing them to pay for their child's care and leaving them enough discretionary income to live comfortably. Parents frequently reported a delay in obtaining services that improve their child's quality of life because they are too expensive to afford out of pocket, yet the process to cover the services through insurance or waivers could take months or became impossible because of restrictive policies. On the question of what would help address these challenges related to state and county benefits and insurance, caregivers most often said: knowing the appropriate office or person to call, having an understanding of the steps in the process and how long it might take, and knowing ahead of time if their benefits might change so they can take action.

50% of community partners felt families were under financial strain due to the need to pay for care and the difficulty in navigating payment options.

The following are caregiver quotes exemplifying this health issue:

Our insurance no longer allows my child to go to speech therapy privately and we can't afford it otherwise. I feel like he is being given up on. They have it at school, but there is a waiting list and they seem to be able to pick and choose their clientele.

I started the waiver process in January, and we are in July and we are still not set up. I literally do emails, phone calls, paperwork several times a week with multiple people back and forth, to try to set this up and is still not set up after 6 plus months.

Our biggest need is money to continue basic things in our everyday life, like keeping a roof over my child's head and keeping the water and electricity on. It is hard to cover the medical stuff and make sure the life stuff is always covered.

Considerations for patient subgroups

- Many challenges facing families with medically complex children still disproportionately impact families living in rural areas. Respondents from all perspectives felt that families living in rural areas, and to a lesser extent those outside Minnesota, still lacked the same level of access to medical and nonmedical services as compared to those who live in the metro area. Receiving services at Gillette is also challenging for them because of distance and the limited implementation of telemedicine. However, it appears that Gillette staff make significant efforts to offset some of these challenges through more thorough coordination of appointments.
- The most medically complex children experience fewer challenges when working with Gillette, yet often have the most needs when utilizing services outside of Gillette. Gillette's Complex Care Clinic provides comprehensive coordination services that help these patients and families experience fewer barriers to addressing their needs at Gillette. However, these families have much more difficulty readily finding urgent care, emergency or primary providers that can serve their children in even basic ways. These families also experience challenges accessing community-based services and have more needs when transitioning home from inpatient stays.

- There were no distinguishable differences in experiences among caregivers interviewed based on race/ethnicity or language spoken. Analysis of caregiver interview data by patient race/ethnicity did not reveal any notable differences in responses. While nearly all families (94%) said staff at Gillette are sensitive to their family's values and customs, due to the smaller number of racially and linguistically diverse families reached, we cannot definitively determine whether there are differences. It is important to keep in mind the significant systemic factors that lead to disparities in medical care and health outcomes for persons of color or patients with more limited financial resources.

Health issues not prioritized

Increased barriers to care when young adults transition from pediatric to adult providers and systems.

Respondents from all backgrounds indicated that as children become adults, their options for receiving medical and support services change, creating the potential for significant disruption in services. Many who identified this concern said there are few medical providers that are prepared to handle medical complexity in adults, and these patients often find themselves aging out of services they may still need. Another challenge during this time is ensuring patients have the option to direct their own care, if possible, and connect with peers who have similar experiences.

- **Gillette's position on this health issue:** Gillette is aware of this challenge and has service lines serving adults through their adult clinics. However, as a children's hospital, they need to maintain an appropriate balance of adult versus pediatric patients, as well as the resources that support them. In addition to their adult clinic services, Gillette is working to support youth as they transition to adult care via a Youth to Adult Transitions grant from the Minnesota Department of Health.

Inadequate availability of appropriate medical and community-based service providers outside of Gillette.

While many organizations such as Gillette specialize in serving medically complex children and adults, many Gillette patients still need to access to medical and nonmedical support services within the community outside Gillette. Caregivers, and to a lesser extent, community partners and Gillette staff, identified insufficient availability of medical and community-based service providers such as: urgent care, emergency care, primary care and mental health providers; therapy services such as physical therapy, occupational therapy, speech therapy or therapeutic medications; and personal care assistants (PCAs), home care and respite providers. Inadequate availability was often attributed to staff's lack of basic understanding of a complex patient's needs, a lack of providers due to geography (respondents in Greater Minnesota and outside Minnesota reported

these challenges most strongly) and the overall lack of access due to waitlists and staff turnover among local providers.

- **Gillette’s position on this health issue:** Gillette will address this issue indirectly through their work in coordinating care, telemedicine and caregiver education, but at this time, the organization does not have the capacity to expand services into all areas of need and in all geographies. Many of these issues within this health need are related to large systemic challenges related to other organizations’ practices.

Overarching systemic challenges prevent families from easily getting their medical and nonmedical needs met.

All respondents discussed policy or systemic challenges that make it difficult for families to manage their child’s care for medical, home and community-based services. Challenges that exemplify the issues within the overall system of care include: insufficient PCAs, home-care nursing and respite services due to poor funding and staffing levels; inconsistent eligibility criteria and processes for accessing insurance and waivers; and services for complex patients spread across many different organizations with different policies and practices.

- **Gillette’s position on this health issue:** At this time, Gillette does not have the capacity to change the way in which they engage with larger systems’ change efforts. However, Gillette will continue to participate in partnerships and collaborative work that supports the improvement of policies and systems that are intended to service children with medical complexity. In addition, Gillette will continue to support parents in their efforts to navigate service systems until larger systemic changes are made.

ABOUT THE PRIORITIZATION PROCESS

In September 2019, Gillette's CHNA team, with support from Wilder Research, led Gillette's Executive Leadership team through a review of all needs identified through Gillette's 2019 CHNA in order to identify priority health issues. The Executive Leadership team considered the following questions during their prioritization process:

- Who is impacted by each need?
- For each need, who might benefit from having the need addressed first?
- What is Gillette's current capacity to address each issue?
- How does each need align with current Gillette initiatives?
- What work is being done outside Gillette to address these needs?
- What is the reach of each need – is the need internal to Gillette, the community level or the state/systems level?
- What does Gillette feel is essential for all patients and families to ensure medical needs are met and quality of life is maximized?
- What needs can Gillette address independently, and what needs could Gillette address through collaboration with other organizations?

UPDATE ON 2016 ASSESSMENT RESULTS AND ACTIVITIES

Priority Health Topic - More Centralized, Consistent And Personal Care Coordination

Care Management Program (including Complex Care Pediatrics Program)

Gillette's Care Management Program follows a two-tier approach. The first tier involves Gillette staff members coordinating a patient's care within a single specialty area, such as, orthopedics or neurology. The second tier is offered to Gillette's most complex patient population, utilizing a team approach to ensure patient care coordination across multiple Gillette specialties, primary care providers and community resources and services. An integral component of this team's work is developing a plan of care.

Gillette's new care management model provides many benefits, including designating a single point of contact for patient families and primary care providers. This eliminates the potential for duplicating tests and procedures, increases efficiency and allows providers to immediately consult with one another to quickly create a care plan.

According to our data, managing conditions through this level of integrated care leads to better overall health for patients and potentially results in fewer emergency department visits and unplanned hospitalizations.

Patient portal (MyGillette)

Gillette's online patient portal was expanded to include the following items in 2018: clinical notes, testing, lab and imaging results, patient visit summaries and messaging directly from Gillette staff members.

Additional items will be implemented in 2019, such as two-way messaging and the ability, prior to the clinic visit, to send forms with pertinent medical information such as current equipment, specific assistance needs, and updated school medications.

Reorganization and improvement of scheduling protocols and processes

Patient scheduling and information systems and technology departments created a template tool to improve and standardize documentation in our electronic health record, along with an education component to ensure accuracy and efficiency for provider documentation.

Longer group appointments for multidisciplinary care teams

Children who have complex medical conditions see providers representing a variety of specialty areas, all of which must coordinate seamlessly with one another. In an effort to best serve these patients, Gillette offers families the option of seeing multiple providers simultaneously. For example, in our Motor Delay Clinic, three specialists—an orthopedic surgeon, a neurosurgeon and a rehabilitation medicine physician—consult with family together.

The following multidisciplinary clinics meet together with the family to develop a treatment plan:

- Aerodigestive clinic
- Brachial plexus clinic
- Complex movement disorder clinic
- Comprehensive epilepsy clinic
- Ketogenic clinic
- Motor delay clinic
- Neuromuscular clinic
- Osteogenesis imperfecta clinic
- Prosthetics clinic
- Rett syndrome clinic
- Spasticity clinic
- Spina bifida clinic
- Upper extremity tone clinic

Priority Health Topic - Greater Access to Appropriate Care and Treatment in Greater Minnesota

Reorganization of care teams and locations to improve consistent access for patients in greater Minnesota

In 2018, Gillette restructured our Greater Minnesota clinic strategy to offer more consistent locations, providers and access for patients. We operate eight clinics throughout Greater Minnesota (Alexandria, Baxter, Bemidji, Duluth, Mankato, Marshall, St. Cloud and Willmar) with the goal of offering appointments at least two days per week at each of these locations.

Increased use of telemedicine to expand breadth of services provided

Gillette introduced new technology that will grow our ability to offer telemedicine appointments to our patients. We also added new providers and specialty services that are available via telemedicine. These changes will improve access to our core services for children living in greater Minnesota, Iowa, South Dakota and beyond. We will continue this expansion to meet the needs of the patients we serve.

Webinar series

Our Partners in Care webinars continue to be held between eight and 10 times per year. These webinars are intended to educate primary care and community providers about the conditions Gillette treats and services available to patients. Providers can view the webinars to receive continuing education unit credits, and recordings are uploaded to gillettechildrens.org. Gillette's Provider and Community Relations team markets these webinars during Gillette-sponsored medical conferences as well as in-person visits with community providers. They are also featured in Gillette's quarterly print newsletter for referring providers.

Priority Health Topic - More Caregiver Support Services

Active promotion of caregiver support services and identification of ways to better connect families to these services

Gillette's Child and Family Services department provides the following emotional and psychological support to patients and families:

- Child life specialists distract our patients during difficult medical procedures and help motivate them during rehabilitation therapies. Examples include offering children virtual-reality goggles for positive distraction to reduce pain and anxiety before a medical procedure, and animal-assisted therapy to motivate children during their hospitalization.
- Social workers help meet patient family needs from an economic, social and community support standpoint.
- Therapeutic recreation specialists help children who have complex conditions adapt recreational and leisure activities, such as skiing, sled hockey or bike riding.
- Board-certified music therapists use music to increase positive behavior and improve quality of life.

Condition-specific health resources

We have transitioned our patient education materials to gillettechildrens.org, our external website. Our online library includes over 400 patient education topics, allowing caregivers to print on demand. Caregivers can also watch educational videos, read about conditions Gillette treats and services offered and discover useful information on our public blog.

Adaptive technology and sports fund

Gillette's Foundation fundraises for this program through two annual community events. Dollars raised help children who have complex conditions purchase adaptive sporting equipment, such as a customized bicycles, or adaptive technology such as computers and keyboards. Caregivers can apply for the fund every spring, and grants are awarded.

Facebook resource groups for cerebral palsy and spina bifida

We have strong and active Facebook resource groups that include cerebral palsy (1,900+ members) and spina bifida (400+ members). In 2018, we created a scoliosis resource group (200+ members) that is growing quickly.

2019 PRIORITY HEALTH TOPICS AND RESOURCES

Priority health topic	Implementation strategies	Gillette resources	Partnerships
Care Management (CM)	<p>Proactively share patients' pertinent care plans (with associated respiratory or seizure action plans) with primary care providers/healthcare home and home-care agencies.</p> <p>Create and implement a one-call access line for patients/families enrolled in CM.</p> <p>For care managers of patients enrolled in CM:</p> <ul style="list-style-type: none"> • Meet with patients and families to create outpatient-centered goals that align with their medical plans of care. • Proactively address transition planning from adolescence to adulthood with the patient and family. • Work to identify potential parental support networks and connect them with patients and families. • Along with social work teams, screen patients for social determinants of health and refer them to the appropriate resources. 	<ul style="list-style-type: none"> • Care managers • Child and Family Services • Complex Care Pediatric Program • Care Management phone line • Family Advisory Council 	<ul style="list-style-type: none"> • NowPow • Family Voices • Primary care clinics • Home health agencies • Minnesota Department of Health • Local social services and community-based organizations
Patient Education	<p>Increase patient and family education offerings and access on GilletteChildrens.org and the patient portal.</p> <p>Enhance patient education modalities at inpatient and outpatient visit discharge.</p> <p>Leverage mobile applications for pre-op and post-op education.</p>	<ul style="list-style-type: none"> • Patient Education Committee • Providers/nursing participation in content creation • Gillette task force for review of new education/television platforms • Information Systems • Family Advisory Council 	<ul style="list-style-type: none"> • NowPow • Family Voices • Primary care clinics • Home health agencies • Minnesota Department of Health • Local social services and community-based organizations
Community Resources	<p>Roll out social determinants of health (SDoH) screening program with NowPow tool.</p> <p>Post a list of community resources for patients and families on external GilletteChildrens.org and patient portal. Examples:</p> <ul style="list-style-type: none"> • Recreational resources for children with adaptive needs. • Resources to help with understanding financial programs available to families with children with complex conditions. 	<ul style="list-style-type: none"> • Child and Family Services • Care managers, inpatient and outpatient • Child and Family Services 	<p>Gillette to formalize community partnerships based on SDoH screening data, identifying most prevalent support needs</p> <p>Examples include: Family Voices and other local social services and community-based organizations</p>

PRIORITY HEALTH TOPICS AND RESOURCES

Priority health topic	Implementation strategies	Gillette resources	Partnerships
Patient Access	<p>Implement a patient engagement platform to facilitate improved communication between patient access staff and families, allowing for multiple methods for outreach and response.</p> <p>Implement self-scheduling functionality for targeted appointments to allow easier direct scheduling and create capacity for remaining in-person and on-phone scheduling.</p> <p>Implement waitlist functionality to allow families to take advantage of late cancellations.</p> <p>Revise workflow to track outpatient order volume and the percentage of orders that convert to active appointments, including the timeframe of an outpatient order and the time from request to first contact to scheduling action and final appointment date.</p>	<ul style="list-style-type: none"> • Patient access specialist • Prior authorization staff • Telehealth • Providers 	<ul style="list-style-type: none"> • Software vendor
Access and Financial Advocacy	<p>Create a financial advocate position within Charge Integrity to work closely with that team as an escalation resource, providing a holistic focus on the patient financial profile.</p> <p>Set up financial advocates as a dedicated resource for patients, families, physicians and staff to assist in answering financial coverage questions and concerns both pre- and post-service.</p> <p>Create alignment for the patient/family financial profile, including payer source alignment lines of business.</p> <p>Increase awareness and participation in the Gillette Assistance Program.</p> <p>Proactively increase patient/family awareness of outpatient facility fees for visits.</p>	<ul style="list-style-type: none"> • Patient access specialist • Prior authorization staff • Telehealth • Financial advocate • Family Advisory Council 	<ul style="list-style-type: none"> • Minnesota Department of Health • Local social services and community-based organizations • Payors

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APPENDIX

Caregiver experiences with Gillette services and staff

Wilder staff also collected information from all caregivers about their experiences with Gillette providers and plan of care, MyGillette patient portal and telemedicine, as well as their overall satisfaction with Gillette. This information can help Gillette staff understand more broadly the experiences of patients and families, as well as the utilization of specific Gillette services.

A1. Experiences with Gillette providers and plans of care (N=202)

	Strongly Agree	Agree	Disagree	Strongly Disagree	DK/NA/ Not needed
Your child's doctors at Gillette make you feel like a partner in their care.	64%	32%	3%	0%	1%
Providers and staff at Gillette are sensitive to your family's values and customs.	61%	33%	3%	0%	4%
You get a plan of care from Gillette for your child in a timely manner.	46%	39%	5%	4%	6%
Your child's plan of care from Gillette helps you understand your child's current condition.	55%	30%	7%	3%	5%
Your child's plan of care from Gillette helps you understand what changes you can expect in your child's condition in the future.	38%	42%	8%	4%	8%
You are able to get appointments with Gillette providers for your child without difficulty.	33%	47%	13%	6%	1%

Totals may not equal 100% due to rounding.

Patient portal experiences

A2. Have you used or accessed the online patient portal called MyGillette? (N=202)

	%
Yes	38%
No, but I know about it	44%
No, and I do not know about it	18%

A3. Which of the following MyGillette features have you used? (N=77)

	%
Clinical notes	77%
Patient visit summaries	73%
Lab results	57%
Other features	31%
Direct messages with Gillette staff	14%

Other features mentioned include: checking appointment dates/times, diagnosis and medication lists. Total percentage equals more than 100% as respondents could check all responses that applied.

A4. Overall, how helpful is the patient portal (MyGillette) to you? (N=77)

	%
Very helpful	56%
Somewhat helpful	36%
Not very helpful	5%
Not helpful at all	1%
NA/Don't know	1%

Total may not equal 100% due to rounding.

Telemedicine experiences

A5. Has your child been offered the option to use a telemedicine appointment with a Gillette provider?

	N	Yes	No	NA/Don't know
By respondent location				
All respondents	202	7%	85%	8%
<i>Did you use the service offered to you?</i>	14	21%	64%	14%
Metro area only	113	3%	87%	11%
Greater Minnesota only	61	10%	85%	5%
Outside of Minnesota only	28	18%	79%	4%
By complex care status				
Complex Care Clinic patient	56	13%	88%	0%
Standard patient	146	5%	84%	11%

Total may not equal 100% due to rounding.

A6. Would you like to be able to use a telemedicine appointment for your child in the future if possible?

	N	Yes	No	NA/Don't know
By respondent location				
All respondents	166	43%	42%	14%
Metro area only	94	40%	40%	19%
Greater Minnesota only	51	49%	43%	8%
Outside Minnesota only	21	43%	48%	10%
By complex care status				
Complex Care Clinic patient	56	60%	24%	16%
Standard patient	146	40%	45%	14%

Total may not equal 100% due to rounding.

Overall satisfaction with Gillette

A7. Overall, how satisfied are you with Gillette Children's Specialty Healthcare? (N=202)

	Very satisfied	Satisfied	Neither satisfied or dissatisfied	Dissatisfied	Very dissatisfied	NA/Don't know
Communication with you	54%	34%	8%	3%	1%	1%
Communication with other Gillette staff about your child or family	51%	30%	8%	6%	1%	5%
Communication with providers outside Gillette	44%	34%	12%	3%	0%	8%
Condition-specific Facebook groups for families	47%	32%	10%	4%	1%	7%

Total may not equal 100% due to rounding.

Wilder Research, a division of Amherst H. Wilder Foundation, is a nationally respected nonprofit research and evaluation group. For more than 100 years, Wilder Research has gathered and interpreted facts and trends to help families and communities thrive, get at the core of community concerns and uncover issues that are overlooked or poorly understood.

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