



**Gillette
Children's**

Specialty Healthcare

120 YEARS OF **CAN**



2016

COMMUNITY

HEALTH

NEEDS

ASSESSMENT

Prepared by:

Lida Gilbertson

Amanda Hane

Rebecca Sales

CONTENTS

Background	3
About Gillette Children’s Specialty Healthcare	4
Description of the community served by Gillette.....	4
Characteristics of patients served by Gillette.....	5
About the Community Health Needs Assessment	8
Data Collection Methods.....	8
Data analysis.....	9
Summary of community health needs and preferences	10
Community health needs and preferences of Gillette patients and families.....	10
Scheduling.....	11
Accessing community services.....	12
Coordinating medical care and treatment.....	13
Themes related to specific population groups.....	15
Priority health issues identified from the assessment	17
Prioritization process.....	17
Key priorities.....	17
Building on past efforts	19
Available resources	21
Next steps	22

FIGURES

1. Demographics of patients served by Gillette	6
2. Most common diagnoses	7
3. Patient access and utilization	7
4. Resources available to address priority health topics	21

ACKNOWLEDGMENTS

We extend our thanks to the many caregivers and providers who shared their experiences and perspectives on the needs of children with complex medical conditions and their families. We appreciate the time and thoughtful feedback given by all who participated in interviews and focus group discussions.

The following Wilder Research staff members also contributed to this report: Jackie Campeau, Amanda Eggers, Melanie Ferris, Rachel Fields, Madeleine Hansen, Nora Johnson, Sera Kinoglu, Nam Nguyen, Stephanie Peterson, Miguel Salazar, Dan Swanson, Lindsey Turner, Ellen Wolter, and Thao Vang.

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 (Gillette) and the process used to conduct the assessment, identifies the health needs prioritized by families served by Gillette, and summarizes resources currently available to address these needs. The report also highlights work completed by Gillette to address needs that emerged during its 2013 CHNA. Information from this assessment will be used by Gillette to develop an implementation plan to respond to the prioritized health needs of the community it serves.

ABOUT GILLETTE CHILDREN'S SPECIALTY HEALTHCARE

Gillette Children's Specialty Healthcare (Gillette) is a not-for-profit hospital and set of clinics specializing in family-centered care for children and adolescents with disabilities or complex medical needs. Gillette also provides core services to limited populations of adults with childhood onset disabilities. Some of their 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: Saint Paul, Duluth, Burnsville, Mankato, Maple Grove, Minnetonka, Baxter, Willmar, and outreach locations through Greater Minnesota. The hospital draws families from across the United States, as well as internationally.

Description of the community served by Gillette

For the purposes of this assessment, the community served by Gillette is defined as children, teens, and adults living in Minnesota who have been diagnosed with a medically complex condition requiring specialty medical, rehabilitation and surgical services.

This community definition was developed using statewide survey data and information provided by Gillette about its current patients.

The national Maternal and Child Health Bureau defines "children with special health care needs" as those who are at an increased risk for a chronic physical, developmental, behavioral, or emotional condition and who require additional health care and health-related services. The National Survey of Children and Youth with Special Health Care Needs estimates that 14 percent of children age 0-17 in Minnesota have special health care needs; this is nearly 180,000 children based on 2015 American Community Survey data. Prevalence rates increase with age: 8 percent of children age 0-5 have special health care needs, while 16 percent of school-age children (age 5-11) and 19 percent of adolescents (age 12-17) have conditions that fall into this category. Special health care needs are also more prevalent among boys (age 0-17) than girls (17%, compared to 12%, respectively).

This state estimate of children with special health needs is larger than the community likely to be served by Gillette, as it includes children diagnosed with conditions, such as diabetes or allergies, that are outside of the healthcare system's scope.

Gillette Children's Specialty Healthcare is named in honor of orthopedic surgeon Arthur Gillette, M.D., who helped found the nation's first hospital for children who have disabilities. We are an independent, not-for-profit children's hospital, and our organization has no affiliation with the Gillette Company or the Gillette brand of personal care products.

Characteristics of patients served by Gillette¹

Gillette serves approximately 25,000 patients and their families annually. All patients served in the last year (November 2015–October 2016) received at least some services at a Gillette clinic in the Twin Cities metro region. 64% of families live in the 7-county Twin Cities metro region, while 26% live in Greater Minnesota, and 9% in another state (9%). In 2015, Gillette served patients from all 87 Minnesota counties, 41 states, and 11 countries.

More than three-quarters of patients who receive services from Gillette are children.

Seventy-nine percent of patients served by Gillette are children age 0–17. Although 72 percent of the patients served are white, Gillette serves a diverse patient population. In 2011, nearly 700 patients spoke a language other than English in their home.

Gillette serves a patient population with a variety of complex medical needs. The largest numbers of children who receive services at Gillette are diagnosed with cerebral palsy; orthopedic conditions, such as severe scoliosis; and epilepsy (Figure 2). Additionally, many of the children seen by providers at Gillette have co-morbid medical conditions that necessitate multi-disciplinary care. Patients averaged just over 2 outpatient clinic visits per year, and 30% have been receiving services from Gillette for more than 5 years (Table 3).

¹ There is some variation in the size of the patient population (N) for these demographic characteristics. Factors accounting for this variation include: data being pulled from different Gillette systems, pulling data for different time frames, the exclusion of small amounts of missing data, and the exclusion of patients that opted-out of Gillette marketing and research activities and those patients that are deceased.

1. Demographics of patients served by Gillette

Race (N=22,937)	N	%
White	16,450	72%
Black/African American	1,480	6%
Asian	804	4%
American Indian/Alaska Native	167	1%
Other	1,854	8%
Unknown	2,182	10%
Ethnicity (N=22,937)	N	%
Hispanic or Latino	1,141	4%
Not Hispanic or Latino	19,264	84%
Unknown	2,532	11%
Language (N=22,626)	N	%
English	21,928	96%
Spanish	370	2%
Somali	184	1%
Other	144	1%
Age (N=21,491)	N	%
Age 5 and under	6,044	28%
Age 6-17	11,003	51%
Age 18+	4,444	21%
Geographic region (N=22,732)	N	%
Twin Cities metro	14,683	64%
Greater Minnesota	5,960	26%
Out-of-state	2,089	9%

2. Most common diagnoses

Condition (N=25,267)	N	%
Cerebral Palsy	3,961	16%
Scoliosis	3,343	13%
Epilepsy & Seizures	2,149	9%
Limb-Length Discrepancy	1,577	6%
Plagiocephaly	1,477	6%
Torticollis	1,128	4%
Hydrocephalus	856	3%
Brain Injury	657	3%

3. Patient access and utilization

Time since first patient visit (N=20,721)	N	%
Less than 1 year	7,537	36%
1 through 5 years	7,016	34%
6 through 9 years	2,509	12%
10+ years	3,659	18%
Average outpatient physician visits (N=22,937)	N	%
Average total visits per month	4,754	-
Average visits per patient per year	2.26	-

ABOUT THE COMMUNITY HEALTH NEEDS ASSESSMENT

In 2016, 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. This assessment process differed in scope from the 2013 assessment in two key ways. First, although Gillette continues to serve a broad geographic region, this assessment focused on understanding the needs of children and families who live in Minnesota and who comprise over 90 percent of Gillette patients, rather than gathering feedback from families in the 5-state Midwest region. Second, whereas the first assessment had a very broad focus to help Gillette better understand a range of issues including regional gaps in various medical specialists and system-level barriers to accessing care, this assessment built on those results by gathering more in-depth information on a smaller set of key topics: access to specialty medical services, care coordination, and availability of or access to community resources. These topics were selected based on staff's understanding of patients' needs, past and current efforts at Gillette, and reviews of the literature. The following questions guided the assessment process

- What are the characteristics of children Gillette currently serves?
- What challenges do families experience in accessing services at Gillette?
- What are the care coordination and communication practices that Gillette currently uses?
- What care coordination support do families want?
- 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?
- What services and supports outside of Gillette are missing or inaccessible to families?

Findings from this assessment will provide a comprehensive view of Gillette's care coordination strengths and opportunities for improvement and will inform other work Gillette has done in this area.

Data collection methods

A multi-method evaluation approach was developed to gather feedback from a variety of individuals who are familiar with the needs of children and adults with complex medical conditions, including caregivers, patients, and Gillette staff. The following describes each of the data collection strategies used throughout the assessment.

Literature review. Peer-reviewed journal articles, grey literature, and secondary data sources, including data available from the Minnesota Department of Health, were reviewed to gather background information to describe common conditions treated by specialists at Gillette and their prevalence rates, as well as information about the characteristics and needs of children with complex medical conditions. In addition, focused literature reviews were conducted to guide the development of data collection tools to best capture information about care coordination.

Telephone interviews with parents of children or adult patients who receive services at Gillette. Telephone interviews were conducted with parents of children or adult patients who receive services from Gillette. A list of parents of children who had received services from Gillette in the previous 12 months was compiled by Gillette staff. In addition, Somali and Spanish-speaking families were oversampled in order to improve the likelihood of identifying culturally specific themes. A letter on Gillette Children's Specialty Healthcare letterhead was sent to the sampled parents, informing them that Wilder Research would be calling them in order to learn more about their experiences accessing services for their child at Gillette and in the community. A total of 240 families were sampled for the telephone interviews, and a total of 98 interviews were completed, for a response rate of 41 percent.

In 2014, Gillette also launched a care coordination pilot program funded through the Minnesota Department of Health. The pilot program was designed to improve care coordination for Gillette patients with the highest level of need who were receiving primary care services from at least one of four small clinics. The program provided families with a care coordination team made up of a nurse, social worker, and scheduler. Gillette and Wilder Research decided to focus the assessment on families that did not participate in the care coordination pilot program, but who had received services from Gillette in the past year in order to identify the ongoing needs of the broader Gillette population.

Focus groups with caregivers of children who receive services at Gillette. Six focus groups were conducted with parents of children who receive services at Gillette. These focus groups were conducted in Saint Paul (two), Duluth, Mankato, Willmar, and Brainerd. Gillette staff helped recruit a total of 30 parents who participated in the focus groups. All parents in the focus groups had at least one child that had received services from Gillette in the previous 12 months and was not involved in any pilot programs Gillette was conducting at that point.

Key informant interviews with Gillette staff. Telephone interviews were conducted with 15 Gillette staff with a role in carrying out or planning care coordination for patients. Staff were asked to describe current care coordination approaches at Gillette, what is most effective for families, how Gillette can more effectively meet the needs of families via care coordination, and what internal policies and practices at Gillette could make this easier.

Data analysis

Qualitative data, including key informant interview and focus group data, were coded and analyzed using ATLAS.ti, where themes are identified and modified throughout the analysis process.

Basic descriptive analysis was conducted for quantitative survey data. Open-ended questions used to gather additional information from parents were coded into key themes for analysis. Illustrative quotes from the interviews and focus groups are used throughout the report to provide more insight into the experiences of children and families.

SUMMARY OF COMMUNITY HEALTH NEEDS AND PREFERENCES

A targeted literature review found very few examples of studies or surveys that asked caregivers of children diagnosed with complex medical conditions to think broadly about their child's health needs. However, the 2009-2010 National Survey of Children with Special Health Needs does offer some insights into challenges families in Minnesota face:

Families would like to see greater communication and coordination between providers. In Minnesota, families report high satisfaction with their doctor and health care providers, but less satisfaction with the communication between their doctor and other health care providers.

Caring for children with complex medical needs impacts families' financial situation and time resources. Nearly one quarter of Minnesota families have reported needing to cut back on or stop working to care for their child, or have experienced financial problems due to caring for a child with special health care needs. The majority of Minnesota families caring for children with special health care needs (82%) spend 1-4 hours a week coordinating or providing specialized care for a child with special health care needs; 6 percent spend 5-10 hours per week, and 11 percent spend more than 11 hours a week providing or coordinating care.¹

Community health needs and preferences of Gillette patients and families

Interviews and focus groups with caregivers were conducted to better understand the health needs of families who have children diagnosed with complex medical conditions. The caregivers who shared their experiences and suggestions through this assessment process lived across the state and had received services from Gillette for varied periods of time. Although all had at least one child with a complex medical condition and had been receiving services at Gillette for at least a year, the specific diagnoses and needs of their children varied, reflecting the diverse patient population served by Gillette.

Despite these differences, caregivers regularly identified wanting more individualized support to meet the needs of their child and family, specifically: faster and more efficient appointment scheduling; increased awareness of and access to community resources; more support when making difficult treatment decisions; and personalized care coordination services. The following health-related needs and preferences for service delivery emerged from the interviews and focus groups with caregivers and staff.

Scheduling

Caregivers appreciated when Gillette staff were proactive in scheduling appointments for them or provided reminders about treatment recommendations, although this type of communication did not happen consistently. Caregivers noted that it was helpful when staff took their relevant information over the phone and called back with appointments already set up or provided reminders about scheduling regular care or treatment. However, caregivers and staff alike suggested that this type of communication did not happen systematically, but depended on the individual staff member helping them out. Caregivers also appreciated the reports or checklists given to them at the end of visits, summarizing recommendations for care.

Then they called me back. In fact, they just got my machine and said this is your time, and if that doesn't work, call back. And that was perfect because then I didn't have to try to call back. It was nice.
– Caregiver

Caregivers discussed the need for a wider range of appointment availability. Caregivers mentioned issues in getting appointments in a timely manner, with some caregivers saying there can be months of waiting for an appointment. They specifically mentioned wanting more evening appointments to accommodate daytime work schedules or to reduce the number of times they need to pull their children out of school. Caregivers in Greater Minnesota also indicated that it would be helpful to have specialists at the outreach clinics more often. Caregivers also described inconsistent steps taken to schedule appointments on the same day. Some caregivers, particularly in Greater Minnesota, described support they received from schedulers to arrange appointments on the same day and to accommodate travel time and family schedules. Other caregivers noted that scheduling appointments on the same day continued to be a challenge. There may be opportunities to provide additional scheduling coordination to better serve families.

It was really difficult to schedule [the] appointments we needed in a timely manner and that's probably always an ongoing issue. Everyone wants it done immediately, but doing the best they can to schedule things as quickly as possible [would be helpful], especially when we're dealing with children in pain or who need something right away. – Caregiver

Offering evening appointments is really nice when they do. I think there should be more of those. Most people work during the day and kids have school and you hate to have to miss those things to get care for your kids. So that would be nice to see more evening and weekend appointments.
– Caregiver

Caregivers expressed frustration with the phone scheduling system. In the past year and a half, Gillette has moved from a scheduling system where families contact the same scheduler for any needs they may have, to a track system in which each patient is assigned a track and calls those schedulers when they need to set up an appointment. Caregivers discussed the issues they had in accessing the right departments via the phone track system. Some described confusion about not knowing which number to call to make appointments, and others shared that schedulers were unable to see schedules or make appointments across tracks, which creates difficulties for families who receive services from a variety of departments. Some caregivers noted that in the past, there was one consistent person they called for appointments and that they have lost this personal relationship in the shift to the new system. Gillette staff echoed this in their interviews: families seem frustrated by the new track system, particularly when they need appointments in multiple tracks.

In terms of scheduling visits, it was very confusing how to even make an appointment. We never really knew who to contact, so we were thrown into the general system and it just wasn't fun. The options from which you choose from in the automated phone system, I didn't understand the breakdown. I had to go to the operator every time. – Caregiver

Accessing community services

Caregivers conveyed the need for greater support in identifying and accessing community services. In the interviews and focus groups, many families indicated that they did not rely on Gillette to help them access community services. At the same time, many caregivers reported that they were often unaware of what services existed. Caregivers expressed particular need for:

- Caregiver support services, such as support groups or peer mentoring programs
- Help with accessing county and state aid
- Activities such as modified sports or support groups for their children
- Adaptive technology
- Non-medical therapies such as art or music therapy

A number of caregivers suggested that it would be helpful to be connected to a social worker or staff person at Gillette on a regular basis who could get to know their families and direct them to available resources or make referrals. Some caregivers also described learning about resources through other families, and that support groups or peer mentoring programs could also play a role in helping caregivers learn about and access community services.

They should have a checklist. Have I talked to these parents about financing? About respite? About a social worker? All of those things need to be discussed. That would make services at Gillette even more valuable. Those programs exist out there. They are there. – Caregiver

It would be... nice seeing that there are other people in the area. It's just me and my daughter. We meet people when we go to the cities, but just knowing what activities or what other services that might be available. And I don't even know if there are any. – Caregiver

Coordinating medical care and treatment

Caregivers described inconsistent support in navigating treatment decisions, especially when there were conflicting recommendations from providers.

In several of the focus groups, caregivers shared experiences of doctors within Gillette providing different, and often conflicting, recommendations for treatment. Some caregivers noted that Gillette staff provided them with enough information to make an informed decision, but others described feeling uncertain which treatment plan to follow and the emotional toll of wanting to make the right choice for their child and not going against their doctors' recommendations. In both interviews and focus groups, caregivers indicated some uncertainty about the extent to which Gillette providers communicated with each other about their children's treatment. Several caregivers suggested that having a central provider or social worker that could help caregivers navigate treatment decisions across specialists would be helpful.

They all have good, valid points of why they feel a certain way, but then I'm stuck in the middle trying to please all of these doctors... because this doctor says don't do it that way, and the other says do it that way... and they're all in the same system and they're the ones that referred me to one another.
– Caregiver

I tried to get [the social workers] to be more prominent in the decision-making or certain services or coming forward when you ask for them because you're unsure how to go about something.
– Caregiver

Caregivers are generally satisfied with communication between their Gillette providers and outside providers. However, Gillette staff who participated in interviews felt that sharing records between health systems remains a challenge in coordinating care. They also noted patients often see many providers and keeping all of those providers up-to-date about care a child is receiving can be difficult.

I would say the biggest [challenge] is the lack of shareable electronic medical records. You need to get in touch with providers over [the] phone and email to request what you need and we are all busy; that is really hard. For example, is lab work already done and did we repeat that because we didn't have that information? – Staff

Caregivers expressed a need for a centralized care coordinator role. Caregivers described this position as a consistent staff member who knows their family history and preferences and would help them schedule appointments, connect them to community resources and activities, answer questions about government benefits, connect them to nurses when they have medical questions, etc. In the interviews, caregivers specifically mentioned having to reach out to multiple people every time they have a request. They also felt that they are missing out on resources simply because they have not talked to the right person who knows which ones might benefit their family.

And having one person... whether it's a nurse or a social worker or just a welcome person, who would help you with all of these little details that aren't really medical but that are a part of it. And someone that would get to know you. They'd know your preferences, you'd feel like they're familiar, or if you call and you need an answer right away, someone you know that they can get you the help.
– Caregiver

It'd be nice to have that intro nurse, someone that could pull together the different departments to make sure they're communicating, that the records are all in the same location, [and] that I could call with some weird google question I had, instead of calling each department to find out if I'm on track or not to get the information. – Caregiver

Staff and caregivers felt that telemedicine could be a promising strategy to address some of the care coordination needs of families, but some caregivers shared concerns about the program. Staff and caregivers felt that telemedicine could help meet some of the care coordination needs of families in Greater Minnesota or with children who needed less intensive care. However, some caregivers described technical difficulties they had encountered using the program and concerns about losing the personal relationships with their doctors.

Telemedicine would be helpful] if your child is stable and they have to prescribe medications or whatever and they just have to check in once a year... Our oldest is high anxiety too, [so] that would really be wonderful. – Caregiver

We do the doctor over the computer and sometimes the computer cuts out or people try to talk at the same time and it is weird. The computer picks up every noise in the background and so it makes it very hard to hear. – Caregiver

Themes related to specific population groups

Families in greater Minnesota

Caregivers in Greater Minnesota reported difficulties with providers outside of Gillette not having the comfort levels or expertise in working with children with complex medical needs. In focus groups, caregivers in Greater Minnesota discussed experiences with providers outside of Gillette not having the rapport or skills to effectively care for their children. These experiences were more likely to occur during one-time visits, such as to the emergency room or urgent care, rather than with regular primary care providers. Others mentioned challenges with school-based physical and occupational therapy.

I feel like Gillette sees the most complex of the most complex, so nothing ruffles them, and here in town, a lot ruffles them. We've had that before - my daughter's heart rate hangs out in the 50s. For anyone who knows heart rates, that's pretty darn low - defibrillator low. The [local] pediatrician says, you have to see the cardiologist right now, and a week later the cardiologist [at Gillette] is like eh, that's what kids with her heart history will often do. – Caregiver

School PT and OT is almost a waste of time, but I have to do it to keep him qualified for other things. I spent an hour teaching my doctor what my son's condition is because he was new. – Caregiver

Adult patients

Caregivers of adult patients expressed a need to be connected to transitional community services. Caregivers of adult patients expressed many of the key themes as caregivers overall. However, they specifically noted wishing that Gillette would be able to connect them with work placement and independent living skills services.

My] child having a plan or a transition as they are moving to adulthood [would be helpful]. They are getting older, here are some places we recommend. They've told me, "Okay, we see people up to this age," but never "and then here's a place we recommend." – Caregiver

We are mostly looking at services after he gets out of school. Looking at guardianship and work after high school. Eventually he'll need work placement services and transition services. – Caregiver

Hispanic/Latino and Somali families

Spanish- and Somali-speaking caregivers expressed a need for culturally specific community services. Generally, Spanish- and Somali-speaking caregivers were happy with their experiences at Gillette and themes echoed much of what was heard in the other interviews and focus groups. Unlike other caregivers, however, Spanish- and Somali-speaking caregivers viewed their interpreter as their point-person or care coordinator at Gillette. They also expressed a desire to be connected with more community services and specifically mentioned wanting to know about culturally specific services that would be available for their children.

They could connect us [to] Spanish speaking organizations that help with family planning, relief services where they would care for our daughter while we can get some time for ourselves.
– Caregiver

PRIORITY HEALTH ISSUES IDENTIFIED FROM THE ASSESSMENT

Prioritization process

The process of identifying priority health issues occurred through a series of discussions with Gillette staff. Wilder Research first presented a summary of key findings from the assessment to the team of Gillette staff who had participated in the planning process. A facilitated discussion was used to determine which issues were most important to address in order to meet the needs of children and families and that were actionable for Gillette as they considered organizational efforts already in place and the feasibility of implementing new changes.

Key priorities

Based on identified need, currently aligned efforts, and the feasibility of implementing changes, Gillette identified three key priority health needs: more centralized care coordination; greater access to appropriate care and treatment, especially in Greater Minnesota; and more caregiver support services.

More centralized, consistent, and personal care coordination

In its care coordination pilot program, families received help with care coordination through a team of a scheduler, a nurse and a social worker. This program involved families with the most complex medical needs, but findings from this assessment indicate that families with more moderate level needs may also benefit from a more centralized model. Families were interested in having an individual or team of staff who they would work with consistently; would get to know their families; and would help them schedule appointments, navigate treatment, and connect with community resources. Families also noted the need for a more centralized scheduling process. Many favorably recalled individual efforts by staff, or previous experiences before the track system was in place, where they could schedule all of their appointments through one point of contact.

Staff also noted that the lack of a standardized care coordination system leads to replication of services and staff working outside of their professional roles, and so establishing a more centralized model could also increase organizational efficiency.

Greater access to appropriate care and treatment, especially in Greater Minnesota

Caregivers were generally satisfied with the care that they received from Gillette, but noted the need for increased appointment availability for specialists, especially at the outreach clinics in Greater Minnesota. Caregivers and staff saw opportunities to continue to expand telemedicine in Greater Minnesota, which may mitigate some of the difficulties families face with appointment availability. Caregivers across regions also noted that more evening and weekend appointments times would be helpful, as well as the ability to schedule appointments after-hours, either through a phone system or an online portal.

Caregivers in Greater Minnesota also described the need for improved care at non-Gillette clinics. Many families in these regions shared that they were hesitant to seek care at non-Gillette hospitals and clinics because of negative experiences with staff lacking the expertise or comfort in working with children with complex medical needs. Parents reported particular challenges with emergency room and urgent care visits, and with school-based physical and occupational therapy services.

More caregiver support services

Gillette offers some parent and caregiver support services, but most caregivers reported that they were not aware of any programs at Gillette and communicated strong interest in parent support groups or peer mentoring programs. Caregivers in Greater Minnesota noted particular need for connections with other families. Some suggested that these services could also play a role in helping families becoming connected to additional community resources, such as activities for their children, or navigating county and state aid programs. Gillette may look into ways to build awareness of current programs and expand its offerings of caregiver support programs.

BUILDING ON PAST EFFORTS

The following twelve health priorities were identified through Gillette’s 2013 CHNA and were the focus of Gillette’s efforts through 2016. A brief summary of the impact of the work done to address each priority area is described below:

Priority health topic	Description of efforts and their impacts
Expanding or enhancing existing satellite clinics	In 2016, Gillette conducted an analysis of Gillette clinic sites in Greater Minnesota which has resulted in a plan to increase patient access through reorganization of clinics, increased use of telemedicine, and development of a model for adding consistent service levels throughout the state.
Identifying ways to improve timely and appropriate referrals to Gillette Children’s Specialty Healthcare	<p>Since 2013, a significant number of providers has been added, including Advanced Practice Providers (APPs) for patient assessment and triage.</p> <p>Efforts are underway to examine barriers to access for patients in some sub-specialties, including evaluation of scheduling protocols, no-show rates, and coordination of appointments.</p>
Facilitating communication between local providers and Gillette providers	<p>Since 2013, Gillette has increased utilization of telemedicine, publications, and webinars to expand their ability to provide education to community healthcare providers.</p> <p>In 2014, Gillette was awarded a \$640,000 care coordination grant from the Minnesota Department of Health (MDH) to pilot a new method for supporting families navigating the healthcare system.</p> <p>Gillette is in the process of developing a Complex Care program to increase communication and coordination among providers caring for patients with the most complex medical conditions.</p>
Exploring opportunities to assist families in navigating out-of-network or out-of-state care	<p>Social workers, therapists, prior authorization staff, and providers are working with payer systems to justify medical necessity for appointments with varying degrees of success.</p> <p>Barriers remain for out-of-state families who want to access some forms of treatment at Gillette due to Medicaid regulations in Wisconsin, North Dakota, and South Dakota.</p>
Working directly with state Medicaid programs and other large health systems to streamline referral and reimbursement processes	<p>Since 2013, Gillette has joined the Minnesota Integrated Health Partnership (IHP) which is an approach to delivering high quality healthcare while reducing costs for Medicaid patients.</p> <p>Gillette’s Complex Movement Disorders program has successfully worked with Medicaid to authorize the use of Deep Brain Stimulation.</p>
Establishing a designated care coordination role to address clearly defined barriers to care for specific patient populations	Gillette is expanding the care coordination efforts initially funded by the MDH grant as listed above.

Priority health topic	Description of efforts and their impacts
<p>Increasing the availability of information and accessibility to communities of color</p>	<p>Gillette has signed the American Hospital Association “#123forEquityCampaign To Eliminate Health Care Disparities” and are implementing processes to better understand the beliefs and values of each family they serve, including a question in the electronic health record. Text reminders are also sent to patients in Hmong and Somali.</p> <p>Since 2013, Gillette has established partnerships with Project Search (to hire individuals with disabilities), Step Up and Right Track (to hire minority interns), and the Central Corridor Workforce Group (dedicated to hiring employees along the transit line).</p> <p>Gillette has continued to partner with Parent-to-Parent and Family Voices who strive to hire staff with diverse cultural backgrounds.</p>
<p>Considering the role Gillette can and should have in facilitating referrals to community-based, non-medical services and supports</p>	<p>Gillette considers this role as part of its ongoing mission and vision to provide comprehensive care.</p> <p>The Gillette social work team continues to work on providing resources for transportation, financial assistance, and appropriate community services.</p>
<p>Exploring opportunities to use technology to improve communication and quality of care</p>	<p>Gillette is undergoing an expansion of telemedicine services.</p> <p>Gillette recently launched a new electronic health record, including a patient portal and text reminders.</p>
<p>Expanding the health care workforce to include more providers and staff of color</p>	<p>Gillette has developed activities focused on hiring and retaining people of color, all abilities, and veterans, including decision-making that stresses the value of diversity; diversity and inclusion values built into department goals; and diversity being added to collateral on the careers website, at career fairs, and in marketing materials.</p> <p>The Diversity and Cultural Competency Committee has analyzed data on current hiring and career advancement opportunities. The human resources department had updated the diversity recruitment strategy to increase the diversity of applicants; this includes partnering with recruitment firms focusing on diversity recruitment.</p> <p>Gillette launched an internal training program for neurodiagnostic technicians with the hope of attracting diverse candidates.</p>
<p>Identifying opportunities to educate parents and community members about prevention of chronic diseases</p>	<p>Gillette is collaborating with Regions Hospital to educate community members about safety and prevention of injury (i.e. helmet and seatbelt safety)</p> <p>Gillette has been working with nonprofit groups and associations to educate the community about the conditions they specialize in. Gillette also works closely with advocacy groups, such as PACER, to educate and raise awareness about bullying prevention.</p> <p>The Complex Care plan that is currently being developed will include a focus on increased communication and coordination among providers who care for this patient population.</p>
<p>Supporting existing early identification and intervention efforts</p>	<p>In 2015, Gillette launched the Motor Delay Clinic as a tool for early diagnosis and intervention for infants and children who are missing milestones, have certain conditions, or were born prematurely.</p> <p>Gillette is facilitating ongoing community education with therapists and school nurses for early identification of some conditions.</p> <p>Gillette has partnered with school districts and primary care providers to educate and assist with identification and intervention earlier in a child's life.</p>

AVAILABLE RESOURCES

While this CHNA was conducted to guide Gillette’s work to support the health and well-being of children with disabilities and complex medical conditions, an effective response to these health priorities is contingent on tapping into internal resources and efforts, as well as coordinated partnerships with external organizations. The table below describes the resources Gillette will draw on the following to develop an action plan to address each key priority.

4. Resources available to address priority health topics

Priority health topic	Gillette resources	Community resources
More centralized, consistent, and personal care coordination	<p>Care management program (including Complex Care Pediatrics) to focus on consistent and individualized plans of care</p> <p>Implementation and further development of patient portal through electronic health record</p> <p>Reorganization and improvement of scheduling protocols and processes</p>	<p>Minnesota Department of Health (MDH), home health and other providers</p> <p>Local social services and community-based organizations</p>
Greater access to appropriate care and treatment in Greater Minnesota	<p>Reorganization and improvement of scheduling protocols and processes</p> <p>Reorganization of model of care to improve consistent access for patients in Greater MN</p> <p>Increased use of telemedicine to increase breadth of services provided</p>	<p>Local community health providers in a wide variety of locations throughout Minnesota</p>
More caregiver support services	<p>Child and Family Services department which includes social work, therapeutic recreation and play and music therapy</p> <p>Health Resource Education Center</p> <p>Information about peer-to-peer support resources</p> <p>Adapted sports and technology fund</p> <p>Facebook resource groups for Cerebral Palsy and Spina Bifida</p>	<p>Parent-to-Parent</p> <p>Family Voices</p> <p>United Cerebral Palsy of Minnesota</p> <p>Special Needs Meetups and Support Groups</p> <p>PACER Center</p> <p>SpecialNeeds.com</p> <p>Public schools</p>

NEXT STEPS

During the next month, Gillette will work with Wilder Research to develop an implementation plan based on findings and the priority areas identified from this process. Gillette plans to consider the findings from the CHNA, alongside key lessons from the current care coordination pilot program, to consider how to best meet the care coordination needs of families at multiple levels of care moving forward.

This report has been prepared by:

Wilder Research
451 Lexington Parkway North
St. Paul, Minnesota
55104
651-280-2700 | www.wilderresearch.org