

2022 Community Health Needs Assessment



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Gillette staff

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CHNA background

The Affordable Care Act requires all not-for-profit hospitals 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, the process used to conduct the assessment, identifies the health issues prioritized and those not, and summarizes resources currently available to address these prioritized needs. The report also highlights work completed by Gillette Children's to address needs that emerged during its 2019 CHNA. Information from this assessment was used by Gillette Children's to develop an implementation plan to respond to the prioritized health issues within the community it serves, which is also included in this report.

About Gillette Children's

Gillette Children's 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 care for a small number of adult patients with complex medical needs who have been Gillette patients since childhood. 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.

Gillette's hospital is based in Saint Paul, Minnesota, with clinics located throughout the state, including Alexandria, Baxter, Bemidji, Burnsville, Duluth, Mankato, Maple Grove, Saint Cloud, Willmar, and two Saint Paul-based clinics. The hospital draws families from across the United States and internationally. Like many hospitals, Gillette Children's has examined and adjusted their care delivery model to adapt to the COVID-19 pandemic as well as ever evolving healthcare needs, piloting new technology and new care constructs in a rapid form to identify how to best meet the needs of patients and families.

Description of the community served by Gillette

Most of the patients served by Gillette Children's are defined by the national Maternal and Child Health Bureau as children with special health care needs, as they are at an increased risk for a chronic physical, developmental, behavioral, or emotional condition and require additional health care and health related services. A subset of this group, who are the most medically fragile and have the most significant medical needs, are termed "medically complex." (Cohen et al. 2011). Another population of patients are at Gillette for short-term specialized services for an acute health concern.

The National Survey of Children's Health estimates that children with special health needs make up 20% of the population of children nationwide and 18% of children in Minnesota, representing more than 237,000 Minnesota children. It is estimated that children with medical complexity account for only 4% of children, or about 52,700 children statewide (National Survey of Children's Health, 2020-2021; American Community Survey, 2021; 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, adults¹ living throughout Minnesota or the surrounding states who need specialized care, whether long-term treatment for a chronic condition or disability, or short-term services for an immediate health concern.

Gillette Children's serves medically underserved populations, such as those impacted by health disparities and those at risk of receiving inadequate care due to geographic, language, financial, or other barriers.² Wilder Research took additional steps during the design and implementation of data collection to ensure perspectives from medically

underserved populations were adequately represented in this CHNA. These steps include:

- Oversampling those living in greater Minnesota and persons of color in the caregiver and focus group sample.
- 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 speaks English. While Gillette’s focus is on serving children age 0-18, 17% of their patient population is age 19 or older. More than 65% of patients live in the 7-county Twin Cities metro, with the remainder coming from greater Minnesota, a state other than Minnesota, or another country (Figure 1).

1. Demographics of patients served by Gillette, May 2021 – May 2022

Race (N=25,728)	N	%
White	17,577	68%
Black/African American	2,347	9%
Asian	1,106	4%
American Indian/Alaska Native	213	1%
Native Hawaiian or Other Pacific Islander	36	0%
Multiracial	466	2%
Some Other Race	1,516	6%
Unknown	2,467	10%
Ethnicity (N=25,728)		
Hispanic or Latino	2,064	8%
Not Hispanic or Latino	22,402	87%
Unknown	1,262	5%
Language (N=25,728)		
English	24,244	94%
Spanish	647	3%
Somali	457	2%
Other	380	1%

Note: Percentages may not sum to 100 due to rounding.

1. Demographics of patients served by Gillette, May 2021 – May 2022 (continued)

Age (N=25,728)	N	%
Age 5 and under	8,234	32%
Age 6-18	13,376	52%

Age 19-25	1,764	7%
Age 26+	2,488	10%
Geographic region (N=25,728)		
Twin Cities 7-county metro	16,907	66%
Greater Minnesota	6,454	25%
Out-of-state and international	2,367	9%

Note: Percentages may not sum to 100 due to rounding.

Gillette serves patients with a wide variety of complex, co-occurring disorders, with the five most common individual diagnoses being limb length deficiencies, gait abnormalities, cerebral palsy, joint disorders, and developmental dysplasia of the hip (Figure 2). About two thirds (67%) of current patients first utilized Gillette no more than 5 years ago. While patients may have more than one payer -Medicaid is a common secondary payer - it is most common for their primary payer to be a commercial payer (58%) or Medicaid (35%) (Figure 3).

2. Most common diagnoses, May 2021 to May 2022

Diagnoses (N=33,052)	N	%
Limb length deficiencies	3,863	12%
Gait abnormalities	3,718	11%
Cerebral palsy	3,666	11%
Joint disorders	3,085	9%
Developmental dysplasia of hip	2,981	9%
Foot deformities	2,860	9%

3. Patient access and utilization, May 2021 to May 2022

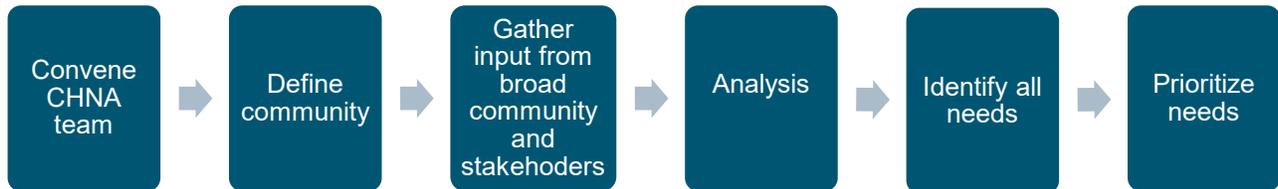
Time since first patient visit (N=25,726)*	N	%
Less than 1 year	4,742	18%
1 through 5 years	12,681	49%
6 through 9 years	2,901	11%
10+ years	5,402	21%
Primary payer (N=25,726)		
Commercial	14,877	58%
Medicaid	8,919	35%
Medicare	1,264	5%
Self-pay	216	1%
Other government	271	1%
Unknown	179	1%

Note: Percentages do not sum to 100 due to rounding.

Assessment approach

In 2022, Gillette contracted with Wilder Research to conduct a CHNA to identify opportunities to improve their services to patients and families. To do this, Wilder gathered feedback from parents, caregivers, and adult patients through an online survey of all caregivers and adult patients and focus groups for a subset of survey respondents. Wilder also conducted key informant interviews with community stakeholders and Gillette staff. (Figure 4)

4. CHNA process



A key aspect of the 2022 CHNA is that it builds upon the 2019 CHNA process, since many of the issues that Gillette children and families face are the result of how systems operate (e.g., health insurance, service delivery for complex conditions, community service providers) and achieving meaningful change to those systems takes time and ongoing coordination. Accordingly, Gillette expanded its understanding of the needs identified in 2019 by again asking questions that aimed to identify emerging priorities, add additional nuance to existing priorities, and elicit thoughts on how priorities can be addressed.

The following questions guided the assessment process:

- What are the experiences of caregivers accessing services and supports?
- What is the journey to diagnosis and care for patients and caregivers?
- What would caregivers and families like to get out of care coordination?
- How is telehealth working?
- What are the family's needs?
- How do Gillette's community partners perceive the partnership?
- How well does Gillette implement policies or practices related to health equity?

Data collection methods

To develop the most complete picture of the needs of children and their families served by Gillette, Wilder utilized a multi-method approach to gather information from families who have children receiving care at Gillette, adult patients, community partner organizations that serve or support these patients and their families, and Gillette staff that are instrumental in managing 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.

Web survey of caregivers of children receiving services at Gillette or adult patients.

Gillette staff compiled a list of all patients who received services from May 2021 to May 2022 and contact information for caregivers. Patients who chose to be excluded from data collection efforts were not included. All records with an email address (20,801 records) received an email inviting them to take the survey online. A total of 1,630 surveys were completed. The demographic characteristics of these respondents, the locations of the patients for whom they were responding, and their relationships to these patients, are provided in Table 5. Respondents were asked to reflect on their needs or the needs 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 resources they utilize as caregivers, and what suggestions they have to improve the systems that serve their family.

5. Characteristics of caregiver survey respondents (N=1,630)

	N	%
Race*		
White	1,242	76%
Black or African American	79	5%
Asian	62	4%
Native American or Alaska Native	9	1%
Native Hawaiian or Other Pacific Islander	3	<1%
Multiracial	30	2%
Some Other Race	62	4%
Unknown/Missing	143	9%
Ethnicity		
Hispanic or Latino	109	7%
Not Hispanic or Latino	1,470	90%
Unknown/Missing	51	3%

Note: Percentages may not sum to 100% due to rounding.

5. Characteristics of caregiver survey respondents (N=1,630) (continued)

Location of patient	N	%
Twin Cities 7-county metro	1,040	64%
Greater Minnesota	344	21%
Out-of-state and international	229	14%
Unknown/Missing	17	1%
Respondent's relationship to patient		
Parent	1,595	98%
Other family member	23	1%
Other (e.g. foster care)	10	<1%
Unknown/Missing	2	<1%

Note: Percentages may not sum to 100% due to rounding.

Focus groups with caregivers of children receiving services at Gillette. Using a subset of caregiver survey respondents who indicated an interest, Wilder Research staff conducted four 90-minute focus groups with 25 caregivers. Participants came from the Twin Cities metropolitan area as well as greater Minnesota, Iowa, North Dakota, and South Dakota. Their children were being or had been seen at Gillette for both short-term care and longer-term ongoing services. Participants were asked what they appreciate most about the way their child receives care from Gillette; whether the care coordination their child receives from Gillette meets their expectations; what the biggest needs they and/or their child have; their experience with virtual care at Gillette; whether anyone at Gillette helps them access services in the community; and whether their child has a care plan and, if so whether they were engaged in developing it.

Key informant interviews with community partner organizations. Gillette staff, with the assistance of Wilder Research, identified nine people at eight organizations that serve or support children with special health care needs and their families that could provide key insights. Community partners represent a variety of perspectives, including human services, community health care providers, specialty health care providers, advocacy organizations, disability service providers, and home- and community-based service providers. Partner organizations were asked to describe what they felt were the biggest areas of need for children with special health care needs and their families broadly and in the existing areas of focus that were identified by Gillette (care coordination/management; early intervention and diagnosis; access to care and treatment; virtual care; and diversity, equity, and inclusion). Stakeholders were asked to describe how family and community strengths can be utilized when addressing these issues, as well as how Gillette might work with their organizations to better address these needs.

Key informant interviews with Gillette staff. Gillette staff identified 18 key individuals that 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, care coordinators, social work staff, and managers of areas such as finance, operations, and interpretation services. 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/management; early intervention and diagnosis; access to care and treatment; virtual care; and diversity, equity, and inclusion). Using their knowledge of Gillette, they were asked to reflect on what could be changed inside and outside the Gillette system to better serve patients and families.

Data analysis

Qualitative data from key informant interviews, surveys, and focus groups 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 and focus groups are used throughout the report to provide more insight into the experiences of children and families.

Health issues identified in 2022

The following health issues were identified through Gillette’s 2022 CHNA. They have been organized by topic according to whether or not the issue is related to Gillette-specific care and infrastructure or is outside the scope of Gillette’s care. Priority health issues were identified through a prioritization process among the Gillette leadership team, with support from Wilder Research. Given the complex, interconnected nature of care these children and families receive, 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, this assessment discusses each issue as a distinct topic.

2022 priority health areas

- Access to virtual care
- Care coordination
- Support for resource navigation
- Transition planning

2022 other health areas not prioritized

- Access to mental health supports
- Shortage of home health care

Priority health areas

Access to virtual care

Gillette Children’s has significantly increased its virtual care offerings over the past three years, offering virtual care for both medical and rehabilitation appointments. Both caregivers and providers agreed that virtual care is beneficial and expressed appreciation for its increased use. Almost all survey respondents (99%) who reported using virtual care for their child’s services said that virtual care met their child’s care need, mostly met the need, or somewhat met the need, and 95% of those who reported using virtual care indicated that the overall experience of virtual care at Gillette was excellent or good. However, there are changes Gillette Children’s could make to improve the virtual care experience for patients and families.

- **Limited use.** While caregivers appreciated being able to use virtual care appointments on occasion, many expressed that it worked well only for a select few appointment types. They noted brief follow-ups and medication checks as the optimal use of virtual care. Additionally, caregivers also had positive experiences with virtual rehabilitation therapy. Half of staff interviewees said that virtual care is not necessarily the best fit for certain appointments (i.e. when providers need to conduct a

physical exam in order to determine progress, diagnosis, etc.), and community-based partner organizations pointed out that patients may also experience technological barriers to accessing care virtually if they do not have the right equipment or access to the internet.

- **Restricted by licensure.** Families residing in Minnesota had the greatest access to virtual care because all Gillette providers are licensed to practice in Minnesota. However, due to state licensing laws, families living outside of Minnesota had limited access to virtual care. A few caregivers noted that their child’s provider is licensed in their state, but this was uncommon. For caregivers in neighboring states, it would be particularly beneficial to be able to utilize virtual care to avoid driving long distances for brief appointments that might not require a physical presence.

The following are caregiver quotes exemplifying this health issue.

Some things I like and some I don't. It's nice to be able to talk to the doctor without [my child] running around. I can keep her in safe controlled environment here [at home] and I'm still able to talk to the doc. So that's helpful. - Caregiver

It's hard to see progress [using virtual care] – I'd rather go in. - Caregiver

Virtual care was good for us. I didn't have to worry about going out and worry about him getting COVID and it killing him. I don't have to worry about him catching something. - Caregiver

Setting up the telehealth for those out-of-state appointments – I think for a while their families got really used to being able to do that, because with COVID, we kind of had that blessing that to go ahead, because we're keeping people in their own states with COVID.¹ And families loved it and then it kind of went away because we lost that short term approval for insurance companies. That's tough. - Gillette staff

Virtual care creates access to care. But families need the equipment and internet access to participate in virtual care. - Community-based organization representative

I feel like in general, we all want virtual care to stay. And we think it is an incredible resource and an ability to provide care to patients that otherwise might not get it. - Gillette staff

With our patient base, there are many times when a virtual appointment just isn't enough. The doctor has to eventually see them physically, do an evaluation physically on them to really get an understanding what's going on. And not having that ability or having families that aren't willing to come in can be a real obstacle. - Gillette staff

¹ Telehealth licensing requirements for delivering virtual care across state lines were loosened during a portion of the COVID-19 pandemic, during which time out-of-state Gillette patients had broader access to Gillette providers via telehealth than is typical under standard regulations.

Care coordination

Both caregivers and Gillette staff acknowledged the challenges of coordinating care for children with special health care needs. Since the last CHNA in 2019, Gillette Children's care coordination has made significant strides, and caregivers' overall outlook for care coordination has improved. Of those with a care manager, 98% said care coordination at Gillette worked very well or somewhat well and supported their overall health outcomes.

When asked about what they notice when care coordination goes well, more than half (56%) of staff interviewees said that the whole care team understands and has access to the plan, as well as having a clear delineation of roles. About one fifth (22%) of staff interviewees indicated that care coordination is time intensive and that it could be improved by increased clarity of roles.

- **Despite the ability for electronic medical record systems to connect, caregivers and providers would like to see notes and records streamlined further.** Despite the ability for Gillette's electronic medical record (EMR) to connect with external EMRs, caregivers perceived an inability to quickly and easily share records across health systems and between providers causes additional strain in the coordination process. Representatives of community-based organizations who collaborate with Gillette echoed the problem of sharing records and the need for more coordination between Gillette and other system providers, noting that "families are overwhelmed by the system." Caregivers also expressed frustration with not being able to see all of their child's records in one place (i.e., the patient portal).
- **The lack of a central staff person(s) who has a comprehensive understanding of a patient and how to meet their needs places excess burden on caregivers.** Gillette Children's care coordination efforts have initially focused on patients in the Complex Care Clinic. Caregivers of these patients had a more positive perspective of care coordination. However, some families that do not have an assigned care coordinator struggle to manage appointments and scheduling.
- **Access.** Nearly half (47%) of caregivers indicated that they did not experience frustration when accessing Gillette. Finding an appointment with their preferred provider was the most common (32%) frustration reported. Additionally, 21% of respondents noted difficulty reaching Gillette by phone, while 14% noted frustration waiting for a call back or follow up from Gillette schedulers.

The following are quotes exemplifying this health issue.

There's just not a super efficient way to do it because you have to involve so many people... The provider ultimately has to say yes. So you're waiting on three providers to be like, "Yeah, that works. No, that doesn't, but this does." - Gillette staff

A lot of times these complex children have multiple specialists across multiple systems, and sometimes mental health care. The toughest thing is just letting the family know what's going on with all the different specialist appointments and follow-ups, and a lot of times we find that medical literacy isn't where it needs to be to manage care without support. – Community Based Organization representative

A lot can fall on the families to help try to explain what one specialist is recommending or doing to another, especially if they're outside of the system. Of course we do everything we can to get records and make that easy, but it's just a cumbersome process and oftentimes there's multiple different care systems involved. - Gillette staff

Our care managers can reach out to all these different specialists. But if the families don't tell us who they're seeing and where, then there's no way for us to know what's happening. So I think it works the best when there's a nice open communication in somewhat real time. - Gillette staff

I think good care coordination, in addition to getting tasks done is also building relationships and being able to think proactively about care instead of just reaction. And at this point, there's no way that the care coordinators can handle that. They are at way overworked numbers of patients that they're seeing and really are in this reactionary model. So I think they're doing tasks, but don't have the bandwidth at this point to actually be able to do true care coordination, which is getting stuff done, but also planning for the future and contingency planning. - Gillette staff

Support for resource navigation

Families with medically complex children often have additional needs outside of medical care such as working with their child's school to secure accommodations, navigating financial support from the county or state, and securing appropriate transportation. Because of the stress on these caregivers, their time available to seek out appropriate resources is limited. Many caregivers expressed a desire for support with finding and accessing these resources, and representatives of the community-based organizations reinforced that assistance identifying community-based resources is needed.

- **Caregivers need a list of available resources.** Families struggle to access resources in part because of limited time. This burden would be reduced if Gillette were able to curate a list of resources for patients and families. The types of resources noted by caregivers ranged from extracurricular activities for children with special health needs (e.g., adaptive sports or camps) to accessible facilities in their communities. Ideally, there would also be someone at Gillette who maintains and regularly updates the list as needed and is able to direct families to particular resources on the list.
- **Completing paperwork and dealing with insurance.** Caregivers with medically complex children are often required to complete extensive paperwork related to their child's needs (e.g., school accommodations, county waivers, insurance claims), and these forms can be challenging to complete. Families expressed a need for help with understanding and

completing paperwork, noting that the process is time-consuming and may have dire consequences if not completed correctly. About two-thirds (66%) of survey respondents reported that obtaining state and county benefits was a challenge.

The following are quotes exemplifying this health issue.

As parents we have so much we're dealing with and adding paperwork would be so much easier to have someone come help and guide us through it. Not doing it for us but having that extra help in all stages. That is a big headache. There should be some kind of help. - Caregiver

[Families] need clinical and community social workers to coordinate care, beyond medical support, to combine clinical information with critical connections to other resources. – Community Based Organization representative

It's important for all of us to recognize that we might have a specialty area in one domain, but [families] often need support and referrals to other organizations. – Community Based Organization representative

I think the best thing is to have some flexibility and just be available for families when they have it. And then the message needs to just be that we're here. Let us know what you need and we'll help you figure out where to get it. Whether that's through us or whether we help partner you with the local community resources or somebody else that's better served. - Gillette staff

There's a group of patients where there are resources available, but they don't know to ask for them. And we don't have a system in place to ensure we're proactively offering all services to every patient. - Gillette staff

Transition planning

For caregivers with adult children, the transition out of pediatric care can be difficult and stressful. Some noted that they felt like resources and support “dry up” as their children got older. These concerns were echoed by representatives of community-based provider organizations.

- **Helping their child find appropriate providers.** Transitioning from a pediatric care provider to an adult provider can be challenging, especially for patients with medical complexity. Families need help with finding the right providers to support their child through adulthood and are cognizant of seeking out providers who can manage their child’s medical condition(s) at the same level of quality that they experienced with Gillette.
- **Finding suitable activities and employment.** Caregivers of children who may never live independently noticed a lack of options for activities and employment once their children were out of school. These caregivers expressed the importance of having meaningful activities available for adults, particularly for supporting good mental health.

The following are quotes exemplifying this health issue.

Transitions from pediatric to adult care are pain points. We need improved continuity in care with pediatrics patients aging out after age 18. We need to improve coordination and management with wraparound services.
- Community Based Organization representative

Young adults and their families have been cocooned in a pediatric system and then the adult system doesn't operate like that at all. And the care gets even more fractured and there's less of a connection and there's no system actively and aggressively working on that, so it's also then frightening for these families.
- Gillette staff

We've been talking about transition to adulthood for decades, and we still struggle with that...how can they have some meaningful employment which isn't just shredding paper or stuffing envelopes and helping their mental health?
- Gillette staff

Really thinking about transition and preparing patients for life outside of Gillette is a big goal that we must think about as we think about improving access. Because if we don't address this, then we're only making it harder for our patients when they go to try to get care at an adult hospital system, where they're not going to talk to families. - Gillette staff

When you get into that adult stage it does change planning. Back when we had an IEP, there was lots of planning and perspectives. We don't experience that kind of structure [anymore]. - Caregiver

Now my kiddo is 26. It's really hard to get appointments for him now. Just because a kid is older, their disabilities do not go away, their need for specialists does not go away...Folks need to think about what they're going to do when their kids are adults. - Caregiver

For me, it's still hard going into the adult world and getting things rolling. It's difficult when you're transferring to the adult side—it's not their fault but it's frustrating when you as a parent have to keep retelling your story. - Caregiver

It's overwhelming...It would be helpful if there were organizations that were cost effective that could help guide you through [the transition from childhood to adulthood] ...I wish there was more help to help transition easier and get resources we need to make sure we do it right. - Caregiver

Other health issues not prioritized

The following health issues related to advocacy were identified during the CHNA but did not fall within Gillette's priority areas. A description of why these areas were not prioritized is also below.

Access to mental health supports

Many caregivers are under significant stress owing to the emotional burden of caring for their child with special health care needs. The difficulty of managing their child's care, coupled with other life stressors, makes it challenging for caregivers to seek out and make time for taking care of their mental health.

- **Caregivers need more opportunities and outlets for support.** While Gillette does offer family services through the social work team as well as parent Facebook groups, caregivers would like more robust support and opportunities to connect more deeply with other parents and caregivers. Many noted that it would be helpful to have a group that regularly meets virtually and is facilitated by a support group leader who is knowledgeable about resources and caregiver needs. Caregivers frequently mentioned that the way they find out about relevant services and resources is from one another, and they often do this through informal means like social media and waiting room conversations. Several mentioned the potential value of offering support groups for caregivers, both for the practical purpose of exchanging information and to offer a social connection for parents, who often feel isolated.
- **Gillette patients need access to mental health care and supports.** In addition to support groups for their own mental health, caregivers expressed a desire for similar groups for their children who utilize Gillette services. They noted several possible benefits, including the ability for kids to see others like themselves, to have a chance to socialize, and potentially develop peer mentor relationships. Beyond support groups, caregivers noted a lack of care resources to support their children's mental health, particularly providers who specialize in working with children with special health needs.

The following are quotes exemplifying this health issue.

Why isn't there something set up for parents to offer us counseling? It's so important, and it would help so many families. I would like them to look more into supporting the family as a whole. It would be nice to talk to someone but our lives are so chaotic, but we need for someone to step up and say, "Hey, parents, take care of yourselves...here's the support to do that." It affects every area of life whether we admit it or not. I wish Gillette would incorporate something like that. – Caregiver

Gillette Children's position on this health issue: Gillette Children's recognizes that good mental health and wellbeing are critical to supporting patients and families. While Gillette Children's does offer some support services such as social work, other mental health services such as psychiatry and psychology fall outside the scope of Gillette Children's core specialties. We will continue to partner with organizations that offer this service in order to support our patients' and families' wellbeing.

Having depression or anxiety as you're taking care of a special needs child when they're first diagnosed and you have to go through that transition of what I really expected this child to be versus what this child is right now. I feel like those are big things and sometimes families aren't able to take care of themselves mentally or physically with respite. - Gillette staff

Shortage of home health care

Families with children who have complex health needs continue to struggle with a lack of available home health care, personal care assistants (PCAs), and respite care. Because their children have extensive needs, support people must have the appropriate skills and training, and when families find someone who is a good fit, there is added stress around what will happen if or when that person moves on (when taking a better-paying job elsewhere, for example).

Gillette Children's position on this health issue:

Gillette Children's recognizes that home and community-based services are critical services used by many patients and families. Gillette Children's continues to evaluate opportunities to incorporate additional home health services into its core offerings while continuing to partner with organizations that offer this service and support patients and families as they navigate service systems.

- **Need for respite.** Many caregivers are burnt out and experience significant mental health issues as a result of the demanding nature of taking care of children with complex health needs. However, they find it difficult to access respite care that can meet their child's needs; this issue is exacerbated for those living outside the Twin Cities.

The following are caregiver quotes exemplifying this health issue.

Home healthcare is a crisis. I think we probably all know that nursing shortages and PCA shortages are to a crisis proportion. So we have caregivers that are up day and night working around the clock. (Gillette Staff)

Considerations for patient sub-groups

- **Many challenges facing families with children with special health care needs still disproportionately impact families living in rural areas.** Providers and caregivers felt that families living in rural areas and to a lesser extent those outside of Minnesota, lacked the same level of access to medical and non-medical services compared to those who live in the metro area. Receiving services at Gillette is also challenging for them due to distance, although the recent expansion of virtual care has helped alleviate this challenge,² at least for certain types of less intensive appointments that can be effectively conducted virtually. Gillette staff make significant efforts to offset some of these challenges through more thorough coordination of appointments so that on-site appointments are consolidated into a single day where possible.

² This is borne out by caregiver survey data, which show that 37% of Gillette patients in greater Minnesota had at least one virtual care visit in the past year, compared to 27% of patients in the 7-county metro area.

About the prioritization process

In September 2022, Gillette's CHNA team, led Gillette's leadership team through a review of all needs identified through Gillette's 2022 CHNA to identify what health issues were to be raised as priority health issues. The leadership team considered the following questions during their prioritizations process:

- What work is being done outside of Gillette to address these needs?
- What is the reach of each need – is the need internal to Gillette, community level, or state/systems level?
- What is Gillette Children's current capacity to address each issue?
- How does each align with current Gillette Children's initiatives and strategic direction?
- What does Gillette feel is essential for all patients and families to have in place to ensure medical needs are met and quality of life is maximized?
- What needs can Gillette address independently and what needs would Gillette need to collaborate with other organizations to address?
- Which of these topics feels the most pressing to address, and how can solutions be designed for the greatest positive impact?

Available resources to address need

Gillette has identified a number of resources to address the prioritized health needs. These resources are specified in the implementation plan table included in this report and include the following:

- Providers
- Nurses
- Nurse Care Managers
- Patient Navigators
- Social Workers
- Rehab Therapists
- Information Services (IS)
- Patient Access Specialists
- Legal and Compliance
- Business Development
- Finance
- Revenue Cycle
- Complex Care Program
- Complex Care Parent Advisors
- Cerebral Palsy (CP) Institute
- Gillette clinical team members
- Marketing and Communications
- Gillette external website
- Identified external organizations dedicated to mental health education and resource identification (e.g., NAMI)
- Transition Committee

Update on 2019 assessment results and activities

Update - 2019 Priority Health Topics and Resources

2019 Priority Health Topic	Implementation Strategies	Gillette Resources	Partnerships	Metrics	2022 Updates
Care Management (CM)	<ul style="list-style-type: none"> Outpatient care managers (OP CM) will meet with patients/families to create patient centered goals that align with their medical plans of care. Patients enrolled in CM will have pertinent care plans (with associated respiratory or seizure action plans) proactively shared with primary care providers/healthcare home and homecare agencies. Create and implement a one-call access line for patients/families enrolled in OP CM. For patients enrolled in OP CM, the care managers will proactively address transition planning from adolescence to adulthood with the patient and family. For patients enrolled in OP CM, the care managers will work to identify potential parent support networks and connect patient and families to them. For patient enrolled in OP CM, the care managers and social work team will screen 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 MN Department of Health Local social services and community-based organizations 	<ul style="list-style-type: none"> 90% of patients enrolled in care management will have an individualized care plan with patient centered goals. 90% of patients enrolled in care management will have an individualized care plan and associated action plans proactively sent to their primary care provider/ health care home. Monitor number of calls to CM line annually (utilization metric). A minimum of 50% of OP CM patients (18y/o or >) will have a goal related to transition to adulthood in their care plan (aim: all patients will transition to adult services by the age of 26.) Monitor (monthly) number of referrals to parent support networks. 90% of patients enrolled in OPCM will complete social determinants of health screen. 	<ol style="list-style-type: none"> Expanded the complex care management team (3.0 RNCM FTE, 2.0 PN FTE) to address the goals/metrics listed below: A minimum of 50% of OP CM patients (18y/o or >) will have a goal related to transition to adulthood in their care plan (aim: all patients will transition to adult services by the age of 26.) <ul style="list-style-type: none"> In progress, submitted proposal to add additional social work FTE to manage transition to adulthood support for all patients 16 and older enrolled in complex care program. 90% of patients enrolled in care management will have an individualized care plan with patient centered goals. <ul style="list-style-type: none"> Revised the care plan document with the support of parent advisors and patient feedback. Added additional RNCM FTE in fall of 2022 to support reaching this goal in 2023. 90% of patients enrolled in care management will have an individualized care plan and associated action plans proactively sent to their primary care provider/ health care home. Closed loop referral system initiated with Family Voices via NowPow platform. Implementation and monitoring of this new process is in progress. Monitor (monthly) number of referrals to parent support networks. Care Management Dashboard in development for complex care program will monitor utilization metrics for the patient navigators and time study information from the care managers and families.

Priority Health Topic	Implementation Strategies	Gillette Resources	Partnerships	Metrics	Updates
					<p>Complex Care Nurse Care Manager and Patient Navigator phone line implemented for families to easily reach the complex care team.</p> <p>Social Needs Health Assessment integrated into the Patient Portal and sent to families prior to complex care clinic visits.</p>
Patient Education	<ul style="list-style-type: none"> • Increase patient and family education offerings and access on GilletteChildrens.org and the patient portal. • Enhance patient education modalities at inpatient and outpatient visit discharge. • Leverage mobile applications for pre-op and post-op education. 	<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 • MN Department of Health • Local social services and community-based organizations 	<ul style="list-style-type: none"> • Access to education is available on the patient portal. • Education content on external website is searchable. • Dot phrases for education content built for commonly utilized education materials. • Organizational wide and mobile education and television platforms evaluated and implemented. 	<ul style="list-style-type: none"> • Cerner Dot phrases for education content built for commonly utilized education materials - There are patient education dot phrases available for asthma, depression, and anxiety. • QR Code Technology for videos/educational materials • Continue to work with NowPow and Family Voices. • TV platform for patient education – a group is being convened to look at options for a new system.

Priority Health Topic	Implementation Strategies	Gillette Resources	Partnerships	Metrics	Updates
Patient Education	<ul style="list-style-type: none"> Increase patient and family education offerings and access on GilletteChildrens.org and the patient portal. Enhance patient education modalities at inpatient and outpatient visit discharge. Leverage mobile applications for pre-op and post-op education. 	<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 MN Department of Health Local social services and community-based organizations 	<ul style="list-style-type: none"> Access to education is available on the patient portal. Education content on external website is searchable. Dot phrases for education content built for commonly utilized education materials. Organizational wide and mobile education and television platforms evaluated and implemented. 	<ul style="list-style-type: none"> Access to education is available on the patient portal - Not available yet, no group currently looking at this although discussion was started pre-COVID on this with IS involvement. Cerner Dot phrases for education content built for commonly utilized education materials - There are patient education dot phrases available for asthma, depression, and anxiety. QR Code Technology for videos/educational materials NowPow and Family voices partnerships continue to be strong. TV platform for patient education – a group is being convened again, led by EOC, to look at the options for a new system.
Community Resources	<ul style="list-style-type: none"> Social determinants of health (SDoH) screening program roll out with NowPow tool. Create list of community resources for patients and families available on external GilletteChildrens.org and patient portal. Examples: 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, IP and OP Child and Family Services 	<ul style="list-style-type: none"> Gillette to formalize community partnerships based on SDoH screening data identifying most prevalent support needs. Examples include Family Voices and other local social services and community based organizations. 	<ul style="list-style-type: none"> 90% of outpatients will be screened for SDoH. 90% of screened patients with a qualifying need will be provided a community referral. Community resource section created on external website. 	<ul style="list-style-type: none"> SDoH - We are screening 73% of all Phalen Complex Care pediatric patients who have a virtual or in person clinic appointment. We have not started screening all outpatients although it remains a goal and use of the patient portal is one modality being explored. 90% of screened patients with a qualifying need will be provided a community referral - 79% of these patients were provided a community referral. Integrated Health Partnership on population management with the state Community resource section created on external website - https://www.gillettechildrens.org/your-visit/patient-services-and-resources/parent-resources-and-support

Priority Health Topic	Implementation Strategies	Gillette Resources	Partnerships	Metrics	Updates
Patient Access	<ul style="list-style-type: none"> Implement a patient engagement platform to facilitate improved communication between patient access staff and patient families allowing for multiple methods for outreach and response. Implement self-scheduling functionality for targeted appointments to allow for easier direct scheduling and create capacity for the remaining in-person and on-phone scheduling. Implement wait-list functionality to allow families to take advantage of late cancellations. 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. 	<ul style="list-style-type: none"> Patient Access Specialist Prior Authorization Staff Telehealth Providers 	<ul style="list-style-type: none"> Notable 	<ul style="list-style-type: none"> Automated outreach and reminders implemented by July 2020. Implement 4 self-scheduling appointment types in 2020. Publish conversion to business dashboard containing statistics related to times between appointment request, first contact, scheduling action, and appointment date to establish baseline metrics by July 2020. 	<ul style="list-style-type: none"> Implemented self-scheduling in Q4 2021 with continued additions in appointments available to schedule. Currently there are ~50 appointments available to direct schedule through the MyGillette portal. Patient messaging to Patient Access was enabled in Q4 of 2021, with billing and prior authorization messaging enabled in Q1 2022. We are working to operationalize clinical messaging. Email and text have been relied on heavily for patient contact to maximize resources. Additional functionalities have been introduced including direct links to the portal to log in or request access, as well as the ability to cancel appointments via text. An online form was developed and implemented to allow for patients to request access more easily to the portal in order to engage in their care A digital release of information portal has been added to MyGillette and the external Gillette website to allow for ROI to be filled out by patients 24/7/365. The ability to request to cancel/reschedule an appointment was turned on in the portal in Q2 2021 which has diverted thousands of phone calls to cancel via the portal. A contract was signed with an intelligence automation vendor, to continue to expand digital access capabilities, namely e-reg and check in functionalities, intake, patient reported outcomes and additional self-scheduling. E-registration and appointment reminders will go live with external vendor in Q4 2022. An appointment request for was developed and is accessible via gillettechildrens.org for all patients, new and established, to request an appointment digitally.

Priority Health Topic	Implementation Strategies	Gillette Resources	Partnerships	Metrics	Updates
					<ul style="list-style-type: none"> A two-way chat functionality was implemented in Q4 2022 for patients with portal access to be able to conduct real-time chats with scheduling staff for appointment coordination needs.
Access and Financial Advocacy	<p>The financial advocate position will be created in Charge Integrity and will work closely with that team as an escalation resource, providing a holistic focus on the patient financial profile.</p> <p>Financial Advocates will be a dedicated resource for our patients, families, physicians, and staff to assist in answering financial coverage questions and concerns both pre and post service.</p> <ul style="list-style-type: none"> Create alignment for the patient/family financial profile, including payer source alignment lines of business. Increase awareness and participation in the Gillette Assistance Program (GAP). Proactively increase patient/family awareness around outpatient facility fee for visits. 	<ul style="list-style-type: none"> Patient Access Specialist Prior Authorization Staff Telehealth Financial Advocate Family Advisory Council 	<ul style="list-style-type: none"> MN Department of Health Local social services and community-based organizations Payors 	<ul style="list-style-type: none"> Two Financial Advocate positions created and filled by September 2019. Increase Shooting Stars Fund candidates matched by 100% over 2018. Increase GAP approvals by 100% over 2018. 	<ul style="list-style-type: none"> Financial Advocates have helped over 300 patients annually get signed up and approved for GAP. Financial Advocates have worked 1 on 1 with hundreds of Gillette families to help them navigate the insurance process – this could take days or weeks and involves speaking with numerous insurance reps and Gillette depts to obtain all the information needed; the Financial Advocate team works as the point of contact so the family isn't left to do all that work themselves. Financial Advocates began creating detailed estimates for our families to educate them on what they would owe on Gillette services. Created new authorization workflows to ensure our patients and families have approved coverage for service prior to their visit. Implemented Presumptive Financial Assistance for GAP funding – families can now qualify for and receive GAP discounts without ever having to apply for GAP. Increase in GAP approvals by more than 100%; this will increase by more than 100% again with presumptive financial assistance. Facility fee information has been updated on our website & we financially screen new patients to educate them on the facility fee.

2022 implementation plan

2022 Priority Health Topics

Priority Health Topic	Specific Initiative	Implementation Strategies	Gillette Resources
<p>Care Delivery & Coordination</p>	<p><i>Access to Virtual Care</i></p>	<p>Giving families the option to meet with their care team virtually is beneficial to families including those that have long distances to travel or have immune compromised children. We aim to increase virtual services in both medical and rehabilitation appointments with the following strategies:</p> <p>Medical:</p> <ul style="list-style-type: none"> • Provide medical virtual care for Regional and select states including virtual clinics in partnership with ChildServe in Iowa, LifeScape in South Dakota, and Sleep Clinic etc. • Assess virtual services in Greater MN • Implement virtual second opinion program • Expand Virtual Pediatric Expert Consults <p>Rehabilitation Therapies:</p> <ul style="list-style-type: none"> • Expand Virtual Rehab Therapies regionally, nationally and internationally • Develop digital applications to deliver synchronous and asynchronous rehab care. Examples: Asynchronous Speech Therapy and GMA assessment for early detection of CP <p>In addition, we plan to:</p> <ul style="list-style-type: none"> • Implement Virtual Joint Seating Evaluation in Greater MN • Develop Gait app to help provide gait services to remote patients 	<ul style="list-style-type: none"> - Providers - Nurses - Patient Navigators - Rehab Therapists - IS - Patient Access Specialists - Legal and Compliance - Business Development - Finance - Revenue Cycle
<p>Care Delivery & Coordination</p>	<p><i>Care Coordination</i></p>	<p>Managing multiple specialists, systems and care plans can be challenging for families. For Gillette’s most complex patients within the Complex Care Clinic and Cerebral Palsy populations, we plan to launch a patient navigation team (Nurse Care Manager, Patient Navigator & Social Work) to proactively co-manage this care with patients and families.</p> <p>To aid in this work we will partner with Gillette’s Information Systems teams to develop necessary patient registries to proactively manage care for the Complex Care Clinic and Cerebral Palsy populations.</p> <p>Formalize partnership with FamilyVoices for closed loop referral system via NowPow or UniteUs platform to provide peer and family support.</p>	<ul style="list-style-type: none"> - Nurse Care Managers - Patient Navigators - Social Workers - Complex Care Program - Complex Care Parent Advisors - IS - CP Institute

Priority Health Topic	Specific Initiative	Implementation Strategies	Gillette Resources
<p>Care Delivery & Coordination</p>	<p><i>Support for resource navigation</i></p>	<p>Mental Health Resources are often challenging to access. Developing mental health resource lists often quickly out of date and are challenging to keep updated.</p> <p>We will identify local and national organizations whose mission is to educate and provide resources to individuals seeking mental health treatment. Links to websites and other pertinent information will be made available on Gillette Children’s external website so that patients and their families can access this information. Additionally, staff can direct individuals to this information.</p> <p>These organizational links will be maintained by Gillette’s social work and communications/marketing teams and reviewed by Gillette’s Family Council to assess value.</p>	<ul style="list-style-type: none"> - Social Workers - Care Managers - Gillette clinical team members - Marketing and Communications - Gillette External Website - Identified external organizations dedicated to mental health education and resource identification (e.g., NAMI)
<p>Care Delivery & Coordination</p>	<p><i>Transition Planning</i></p>	<p>As a pediatric facility, it’s critical for our patients and families to have a plan to navigate their healthcare as they transition to adulthood. We will work to provide proactive transition support and resources to all patients aged 16 years and over enrolled in the Complex Care Clinic Program. This will include partnerships with Social Work and Nurse Care Manager with families to transition patients to the necessary adult medical providers and community resources.</p> <p>We will also consider partnerships with adult primary care clinics in the Twin Cities metro and those outside of this region within Minnesota to establish standard handoff processes for adult patients transitioning to their clinical practice.</p>	<ul style="list-style-type: none"> - Transition Committee - Complex Care Program - Nurse Care Managers - Social Workers - Complex Care Parent Advisors

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