



# 2025 Community Health Needs Assessment



Authors: Sera Kinoglu, M.A., and Carrie Au-Yeung, M.P.H.

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## COMMUNITY PARTNERS

The community partner organizations below offered valuable insights into the needs of children with medical complexity, the systems that support them, and the communities in which they live. These organizations include: Park Nicollet Minneapolis, Metropolitan Pediatrics, South Lake Pediatrics, HealthPartners, and the Minnesota Department of Human Services, Disability Services Division.

## GILLETTE CHILDREN'S STAFF

A number of team members from Gillette Children's worked closely with us in the design and implementation of this community health needs assessment: Kelly Sjostrom, Andrea Stoesz, Stacy Mays, Regan O'Reilly, and Andrew Nesbitt. This Gillette team informed the assessment design; provided data, information, and insight into Gillette's patient population and services; and connected us with other staff and providers as well as community partners.

Gillette staff participated in one-on-one interviews, sharing key insights into the needs of Gillette patients and families and the way that Gillette provides services to them. These staff include:

Tori Bahr, MD, Heidi Davis, Jill Gettings, MD, Tim Getsay, Tenner Guillaume, MD, Margaret Idell, Maria Lamers, Micah Niermann, MD, Pat Nolan, Andrea Paulson, MD, Kali Schreiner, and Matthew Witham.

# CHNA background

Under the federal Affordable Care Act, all not-for-profit hospitals are required every three years to conduct community health needs assessments (CHNA) that identify the health needs and priorities of the communities they serve and the steps the hospitals will take to address these issues. This CHNA report describes the community served by Gillette Children's and the process used to conduct the assessment, identifies the health issues prioritized and those not, and summarizes resources currently available to address prioritized needs. The report also highlights work completed by Gillette Children's to address needs that emerged during its 2022 CHNA. Gillette Children's will use this information to develop an implementation plan to respond to the 2025 prioritized health issues within the community it serves.

# 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 disabilities and complicated medical needs. Gillette also cares for a small number of adults with childhood onset disabilities. Some of Gillette's specialty areas include pediatric orthopedics, neurology, neurosurgery, physical medicine and rehabilitation, and complex pediatrics. Caregivers 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.

Based in Saint Paul, Minnesota, Gillette has clinics across Minnesota, including Alexandria, Baxter, Bemidji, Burnsville, Duluth, Mankato, Maple Grove, Saint Cloud, Willmar, and two clinics based in Saint Paul. The hospital draws families from across the United States and internationally, seeing patients with a range of conditions affecting the muscles, bones, brain, and nervous system.

## COMMUNITY SERVED

Most of the patients served by Gillette Children's are children with special health care needs, according to the definition used by the Maternal and Child Health Bureau of the Health resources and Services Administration (HRSA): They are at an increased risk for a chronic physical, developmental, behavioral, or emotional condition and require more specialized health care and health related services (HRSA, 2025; McPherson et al., 1998). 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 utilize Gillette for short-term specialized services for an acute health concern (e.g., fractures, concussions).

### **By the numbers: Children with special health care needs and medical complexity**

The National Survey of Children's Health estimates that children with special health needs make up 20.8% of the population of children nationwide and 21.3% of children in Minnesota, representing more than 276,165 Minnesota children. It is estimated that children with special health care needs who are medically complex account for approximately 1.5% of children in the United States, which translates to about 19,485 Minnesota children (Minnesota Compass, 2025; National Survey of Children's Health, 2022-2023; Yu et al., 2021).

For the purposes of this assessment, the community served by Gillette is defined as children, teens, and, to a limited extent, adults<sup>1</sup> living throughout Minnesota or 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 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. About 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 April 2024 – April 2025 (N=25,793)

| Race                                      | #      | %   |
|---|--------|-----|
| White                                     | 17,747 | 68% |
| Black/African American                    | 2,730  | 11% |
| Asian                                     | 1,350  | 5%  |
| American Indian/Alaska Native             | 343    | 1%  |
| Native Hawaiian or Other Pacific Islander | 31     | 0%  |
| Multiracial                               | 546    | 2%  |
| Some Other Race                           | 1,696  | 7%  |
| Unknown                                   | 1,530  | 6%  |
| Ethnicity                                 | #      | %   |
| Hispanic or Latino                        | 2,509  | 10% |
| Not Hispanic or Latino                    | 22,302 | 86% |
| Unknown                                   | 1,162  | 4%  |
| Language                                  | #      | %   |
| English                                   | 24,065 | 93% |
| Spanish                                   | 856    | 3%  |
| Somali                                    | 537    | 2%  |
| Other                                     | 515    | 2%  |

<sup>1</sup> Adults who started at Gillette as children would also be included in the population, but Gillette does not focus care on adults.



**1. Demographics of patients served by Gillette April 2024 – April 2025 (N=25,793)  
(continued)**

| <b>Age</b>                 | <b>#</b> | <b>%</b> |
|----------------------------|----------|----------|
| Age 5 and under            | 7,963    | 31%      |
| Age 6-18                   | 13,480   | 52%      |
| Age 19-25                  | 1,897    | 7%       |
| Age 26+                    | 2,633    | 10%      |
| <b>Geographic region</b>   | <b>#</b> | <b>%</b> |
| Twin Cities 7-county metro | 16,811   | 65%      |
| Greater Minnesota          | 7,036    | 27%      |
| Out-of-state               | 2,126    | 8%       |

Gillette serves patients who have a wide variety of complex, co-occurring disorders, with the five most common individual diagnoses being limb length deficiencies, scoliosis, developmental dysplasia of the hip, cerebral palsy, and epilepsy (Figure 2). Nearly two-thirds (65%) of current patients first utilized Gillette no more than 5 years ago. Patients may have more than one payer for their care at Gillette, but it is most common for their primary payer to be a commercial payer (56%) or Medicaid (36%) (Figure 3)

**2. Most common conditions, April 2024 to April 2025**

|                                    | <b>#</b> | <b>% of all patients (N=25,973)</b> |
|------------------------------------|----------|-------------------------------------|
| Limb Length Deficiencies           | 8,219    | 32%                                 |
| Scoliosis*                         | 6,159    | 24%                                 |
| Developmental Dysplasia of the Hip | 5,544    | 21%                                 |
| Cerebral Palsy                     | 4,776    | 18%                                 |
| Epilepsy                           | 3,414    | 13%                                 |

*\*Includes idiopathic, neuromuscular, and other forms of scoliosis. In cases where a patient has received multiple diagnoses in this category, the patient is counted only once.*

### 3. Patient access and utilization, April 2024 – April 2025 (N=25,793)

| Time since first patient visit | #      | %   |
|--------------------------------|--------|-----|
| Less than 1 year               | 5,289  | 20% |
| 1 through 5 years              | 11,670 | 45% |
| 6 through 9 years              | 2,867  | 11% |
| 10+ years                      | 6,147  | 24% |
| Primary payer                  | #      | %   |
| Commercial                     | 14,530 | 56% |
| Medicaid                       | 9,387  | 36% |
| Medicare                       | 1,350  | 5%  |
| Self-pay                       | 345    | 1%  |
| Other government               | 254    | 1%  |
| Unknown                        | 107    | 0%  |

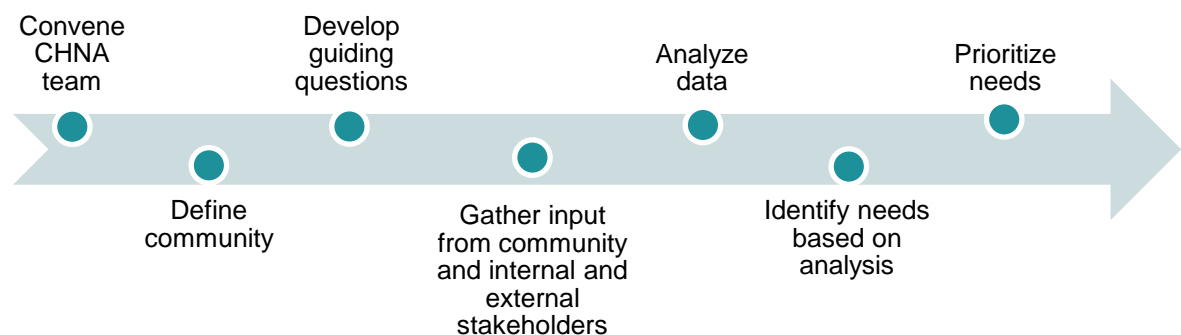
Note. Percentages may not sum to 100 due to rounding.



# Assessment approach

In 2025, Gillette contracted with Wilder Research to conduct a CHNA with the goal of identifying opportunities to improve their services to patients and families. In collaboration with Gillette staff, Wilder developed and administered an online survey for caregivers and parents of Gillette patients and conducted focus groups with caregivers and parents in both the 7-county metro area and greater Minnesota. In addition, Wilder conducted key informant interviews with community stakeholders and Gillette staff.

## 4. CHNA process



The 2025 CHNA builds upon the 2022 CHNA process, which built upon the 2019 CHNA process. The iterative nature of the CHNA process for Gillette Children’s is due to the systems-based nature of the issues that Gillette children and families face. These issues are largely the result of how complicated systems (e.g., health insurance, service delivery for complex conditions, community service provider operations) function. Achieving meaningful change to those systems takes time and ongoing coordination and planning. For each new CHNA cycle, Gillette expands on its understanding of the needs identified in the prior CHNA by asking questions that: add additional nuance to existing priorities, aim to identify new and emerging priorities, and elicit thoughts on how priorities can be addressed.

The following questions guided the 2025 assessment process:

- How well does Gillette embody its values? What can Gillette do differently to emphasize these values?
- What is going well with communication and care at Gillette? What are the challenges?
- How well is Gillette’s approach to transition to adult care working?
- Is genetic testing and counseling being utilized? Would an increase in the availability of genetic testing and counseling services at Gillette be beneficial?

- Are Gillette patients using psychiatric services? Would it be beneficial if these services were available at Gillette?
- Do caregivers and providers understand how to transfer Gillette patients to Gillette inpatient care from an emergency room? How is this process going?

# 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. Wilder staff gathered information from families who have children receiving care at Gillette, community partner organizations that serve or support these children and their families, and Gillette staff who 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 (age 0 to 17) who received services from April 2024 to 2025 along with contact information for caregivers. Gillette staff sent an email to the caregivers of these patients in all cases where the patient contact information included a caregiver email address (19,525 records).<sup>2</sup> The email invited the caregivers to take an online survey about their family's Gillette experience. The first 400 respondents received an incentive of \$10. (Additional respondents could complete the survey after all of the incentives were redeemed if they were still interested. These participants were informed in advance that the incentives were no longer available.) A total of 1,288 caregivers and 361 adult patients completed the survey. Respondents were asked to identify interest or participation in certain specialty services. 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.

## **Interviews with community stakeholders**

Gillette staff, with the assistance of Wilder Research, identified organizations that serve or support children with special health care needs and their families that could provide key insights. From this list, Wilder heard from 5 individuals representing a variety of perspectives, including human services, community health care providers, specialty health care providers, and disability 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 concern that were identified by Gillette. Stakeholders were also asked to describe how Gillette might work with their organizations to better address these needs.

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<sup>2</sup> Caregivers of patients who opted to be excluded from data collection efforts at Gillette were not contacted.

### **Interviews with Gillette staff**

Gillette staff identified 12 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 physicians, nurses, social work staff, department heads, and managers of areas such as finance and operations. 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 certain areas of concern (genetic and psychiatric services; emergency care; transition planning). Interviewees were also asked to describe communication and coordination processes both within and outside of Gillette.

### **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 three 90-minute focus groups with 23 caregivers. 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; their perspectives of the process to get an initial appointment with Gillette; what the biggest needs they and/or their child have; and their experiences with and recommendations for Gillette's communication with patients and caregivers. All participants received a \$50 incentive as an acknowledgement and appreciation for their time.

## **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 areas identified in 2025

The following health areas were identified through Gillette's 2025 Community Health Needs Assessment. Priority health areas were identified through a prioritization process among the Gillette team members, with support from Wilder Research. Given the complex, interconnected nature of care these children and families receive, there is some overlap in the health areas identified. While the interaction between these different areas will be considered as Gillette moves forward with addressing the areas facing children and families, this assessment discusses each area as a distinct topic.

## 2025 priority health areas

- Access to pediatric specialty care and services
- Caregiver support and support for resource navigation
- Rural health care
- Transition planning

## PRIORITY HEALTH AREAS

### PRIORITY 1 ACCESS TO PEDIATRIC SPECIALTY CARE AND SERVICES

Many families and caregivers of children with special health needs experience barriers to accessing appropriate care, particularly for specialist providers. Some caregivers who participated in a focus group commented on the need to visit multiple clinics and health systems in order to meet the needs of their child. Aside from the logistics associated with access to care, participants from caregiver and provider groups noted challenges related to the cost of care, which may further prevent access.

**Given the [political] issues more recently and issues in DC, Medicaid cuts will become the more immediate, most pressing issue. Coordination and access will be exacerbated.**

**– Gillette Provider**

### Patient and family access

Caregivers who participated in a focus group expressed concerns about being able to see their preferred providers. These participants described **difficulties with accessing providers, particularly within a timely manner**. Survey responses from caregivers also suggest some interest in the availability of a pediatric expert phone consult option and would have found this

helpful prior to becoming a patient; 50% of survey participants indicated interest in this possibility.

Appointment availability was also the most frequently-identified frustration among caregivers of current Gillette patients who participated in a survey; 26% of participants said that this was a key frustration. And, when asked about recommendations in an open-ended question, caregivers again suggested addressing appointment availability for Gillette specialists. Some stakeholder interviewees also commented on the need for easier access to care across health systems, citing key issues related to wait times, services needed, and clinic capacity for new patients.

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There has been a lot of staff turnover in recent years. We have had to find several new providers. I have also found that I can have my child seen more quickly at other medical providers than I can get in at Gillette and have moved my child's care elsewhere because of that. I am repeatedly asked to schedule appointments online but frequently have them rescheduled because they were not correct. However, if I call the scheduling line, I get bounced around to different offices/specialties before I get scheduled. – *Caregiver survey participant*

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### Community partner access

When asked about areas for improvement for Gillette, some stakeholders who participated in an interview commented on **difficulties getting a hold of Gillette specialists**. These participants mentioned the time-consuming phone process, which can be hard to navigate as a physician; in particular, some outside providers may experience challenges with reaching a specific department or provider.

Another concern that arose from interviews with stakeholders was the **cumbersome process to share health records**. Participants mentioned the need for a more direct line of communication with Gillette specialists, which would help the providers involved to provide better and more efficient care.

### Access to specialty care

Caregivers who participated in a survey were asked about their engagement with and interest in selected specialties; Gillette providers were also asked to speak about these topics.

## Genetics

More than one-quarter (28%) of caregivers said they had seen a genetic counselor, and 11% of those participants met with a genetic counselor at Gillette. These caregivers most often reported receiving genetic testing (85% of those who met with a counselor), and a little over two-thirds of them said they met with a geneticist (69% of those who met with a counselor). Of those who received services, a little more than one-third (36%) said it changed the course of care for their child. About one-quarter (27%) of all caregiver participants indicated interest in learning about gene therapy trials. Of the Gillette providers who participated in an interview, half (n=6) said that they **anticipate increasing demand for genetics services**, and 5 mentioned that they were in favor of increasing genetics services.

## Psychiatry

While Gillette providers and community stakeholders were both asked questions about psychiatry during interviews, most of these participants spoke mainly about mental health services more broadly. More than half (n=7) of the Gillette providers interviewed expressed concerns about not having enough mental health providers to meet demand. Many of these providers also commented on the **complex nature of mental health services for Gillette's patient population**. Stakeholder interviewees also mentioned this challenge, noting that the wait times to receive diagnoses and connect with appropriate therapies and therapists can be significant.

Among caregivers who participated in the survey, just 16% said that their child had received psychiatry services in the past two years. This rate was higher among adult patients, with 25% reporting that they received such services.

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[There is a] flat out refusal by some psychiatrists to even see our patients. [They're] too complex, nonverbal, so they don't qualify for their services.

– Gillette provider

It's all more complicated when you then add other neurodevelopmental disorders on top of it, and then you add medical trauma and all the other things they've gone through because of their diagnoses and appointments. – Gillette provider

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Finding psychiatric/mental health care support is challenging. Especially having to make multiple phone calls or explaining the multiple health care challenges that their child has and determining if the provider is the right one for them--that becomes really challenging.

– *Community stakeholder*

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## PRIORITY 2 COMMUNITY PRESENCE

The topic of Gillette’s community presence arose in all participant groups, with individuals commenting on overall awareness of Gillette as well as its engagement with community. These participants suggested that Gillette should **expand its presence in the community in order to further build awareness of its specialties and services.**

Among Gillette providers, close to half of interview participants (n=5) mentioned the need for greater community collaboration, including with providers and clinics outside Gillette. Some of these providers further suggested that increased collaboration in this realm could lead to stronger partnerships, thereby improving the coordination of care across systems. In particular, initiating and maintaining strong relationships with primary care could lead to improved health for Gillette patients.

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Primary care is not set up by the system to be successful in caring for these patients. We need more collaboration with primary care doctors to fully optimize [their care]. – *Gillette provider*

I think the thing that makes [coordination] successful is when there’s a relationship that’s been formed with the outside provider and Gillette – when we can reach out and discuss directly. – *Gillette provider*

A number of years ago when Gillette started their complex care clinic, we had the opportunity to meet providers who were part of this complex care clinic and learn about the mission – what the idea was, and how they were going to care for kids. We connected and developed relationships with their support team...I got to know the complex care coordinator nurses and other supportive roles, which was tremendously helpful. I could call them and ask questions about a mutual patient, or if I had to leave a message they would call me back, because we knew each other. Those relationships are really helpful. It really makes that coordination more personal and expedited. – *Community stakeholder*

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### PRIORITY 3 CAREGIVER SUPPORT AND SUPPORT FOR RESOURCE NAVIGATION

Caregivers, providers, and stakeholders all commented on the overwhelming amount of information and systems that must be navigated with a child who has special medical needs. Many caregivers are juggling a number of aspects related to their child's care, including appointment scheduling, insurance claims, county waivers, home care resources, and school supports. As a result, there is a high need for deeper caregiver support with navigating systems and resources.

#### Care coordination and system navigation

Because of the complexity of needs present for many Gillette patients, **caregivers often struggle with managing services or providers spread across different medical systems or clinics. This challenge is further complicated by the need to balance the medical needs and care plans with day-to-day support** and resources required for many Gillette patients. This requires a high level of coordination, which some families may not have the resources to navigate. More than half (n=7) of the Gillette providers who participated in an interview mentioned system navigation support as a critical need. Stakeholder interviewees also commented on this need, emphasizing that strong connections and partnerships between primary care providers and specialists is needed for effective treatment.

Outside of the medical system, caregivers are often tasked with navigating additional supports or resources, such as school interventions, adaptive technology and equipment, and waivers. Half of Gillette providers interviewed (n=6) mentioned a need for more social work support.

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I think parent engagement and making sure ALL families understand their rights and what they have access to is important. I am well-educated and well-versed, and still often get confused or find it hard to navigate. I think there are many more families in MN that aren't even accessing a waiver, which is another whole thing. –  
*Caregiver survey participant*

What I would love to see is a dedicated social worker right there in clinic that could start with that family, meet them, talk through things, have consistent follow up. –  
*Gillette provider*

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Social work [staff] works hard to assist with connecting families to a county worker [that can] help find funding for equipment and transportation services. Other providers could be more knowledgeable – being aware of steps we need to take to get them connected, or knowing what social work can help with. – *Gillette provider*

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## Family well-being

Five providers mentioned awareness of community resources as a key need, and this theme was frequently mentioned by caregivers in both the survey and focus groups. **Caregivers noted the importance of having community resources available, including for social activities or connections with other families.** “You don’t know what you don’t know” was a common refrain among focus group participants, with these caregivers describing different ways they sometimes learned about community opportunities (e.g., adaptive sports). Relatedly, some caregivers expressed an interest in participating in family support groups both in person and online (e.g., Facebook groups).

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I would love to see support groups for specific things created by or initiated by Gillette. My daughter feels very alone in her scoliosis but there are many children who feel that way and could support each other if given the space. – *Caregiver survey participant*

We have all these great events, but I don't know if families know that those are happening, or necessarily getting the invites, because I feel like I hear that from families a lot of; “oh, I saw on Instagram that this happened at the hospital. My kid would have loved that, but we didn't know it existed.” So I think that that communication and outreach to families about upcoming events is something that a lot of people are really wanting. – *Gillette provider*

I feel like families aren't aware of all the resources in the community. There are so many opportunities out there. Whether it's funding for equipment, support groups, social groups, or resources within the county and the schools. And they're just not necessarily aware of it.  
– *Gillette provider*

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I've learned so much sitting in Gillette waiting rooms from other special needs parents...my daughter's in adaptive baseball now, and she's been doing that now since she's been four. But I never knew of any of that until I sat in a waiting room at Gillette talking to other parents. – *Caregiver focus group participant*

I have recently been asked by some families about how to find a family support group, camps for kids with certain conditions, or community activities to help support kids with certain conditions. I feel like Gillette may have a very good idea of some of those resources [and] I think it would be lovely to understand how we can help families connect with resources like that through Gillette. – *Community stakeholder*

Sometimes I think that if you just don't know what questions to ask, you can miss opportunities for better care. I think maybe care providers forget how much they know, and how much the parents don't know, or how to navigate medical systems in general. So I wonder, what are some ways to help educate the parents, so that then maybe they can be a better advocate for their children. – *Caregiver focus group participant*

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## Gillette's communication with families

Caregivers who participated in the survey were asked to indicate **interest in patient education videos** covering specific topics. More than half (53%) of participants said they would be interested in videos on what to expect on their child's care journey, and half of participants would like videos with more information on follow-up care.

Caregivers who participated in focus groups also expressed a desire for overall **improvements to communication** received from Gillette. Survey participants who responded to a question asking how Gillette could better demonstrate its values frequently mentioned the need for more or better communication. Caregivers who cited this issue often described situations in which they felt they were lacking thorough information from Gillette about their child's care, or who had a difficult time reaching providers with questions about what to expect for certain procedures or visits.

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We came to Gillette unexpectedly...we had no experience with hospitals before. We thought it would be amazing to have a kids book in the room when new patients move in, sharing a bit about what to expect at the hospital from the voice of a kid...for example, what amenities there are, what will happen, where kids can go, how will they eat, where/when will they take a bath. Just the basic things, so it's

not so scary.

– Caregiver survey participant

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## PRIORITY 4 RURAL HEALTH CARE

Health care access challenges may be exacerbated for families in greater Minnesota due to fewer clinics and providers located nearby; this issue is even more significant for caregivers who have a child with special medical needs. The distance to travel to Gillette from home was mentioned by several participants in the caregiver focus groups, and five providers mentioned **transportation** as a critical need for patients' families.

Some caregivers noted an interest in Gillette investing more resources in **providing high-quality virtual care**, as these types of visits could help bridge the gap between appointments that require in-person services. Importantly, access to virtual care is limited to those who have high-speed internet, which can be a barrier for some in rural areas.

Beyond virtual care, some Gillette provider interviewees suggested initiating and maintaining **partnerships with providers in rural areas**. With these relationships in place, Gillette would be positioned to provide education or consultation to providers who may see pediatric patients with special or complex needs.

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It's hard with limited internet connectivity sometimes, but we can still grow this method of reaching folks. We can also partner with local providers for education and virtual care. So there's an in-home option and also Gillette provider to local provider with family option. – Gillette provider

Transportation is consistently a huge issue. Some families understand that they can use insurance for this, but often even if they apply for a ride it doesn't happen, so getting to appointments in rural areas is hard. – Gillette provider

With patients in rural Minnesota, the struggle has been greatest [with] getting access to services, being able to come into the cities, trying to get everything done all at once, but lacking supports back in their home town. They're lucky if they have a primary care doc who knows them. But I hear that "local ER is afraid of my kid;" "Primary care does vaccines but we try to do everything else at Gillette." It's a very common issue for folks in greater MN. – Gillette provider

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## PRIORITY 5 TRANSITION PLANNING

The transition from pediatric to adult care for those with complex diagnoses or who have special medical needs is particularly challenging. Patients who have received care at Gillette as a child often struggle to find **providers who can meet their needs** in the same way that Gillette did. Gillette providers who participated in an interview also reported that many adult primary care providers are not well-equipped to take on patients with complex medical histories.

During pediatric patients' teen years, many Gillette providers begin transition planning with their patients' families; 8 of the providers interviewed reported "planting the seed" early on. However, this process is approached differently across specialties and providers. Some caregivers who participated in a focus group indicated **confusion about transition planning**, and just 40% of caregivers taking the survey said that it was clear when transition should take place. When asked about recommendations for Gillette, adult patients who responded to the survey most often suggested that adult services be expanded or implemented in a more intentional way.

Caregivers also expressed a desire for **stronger supports and resources during the transition phase**, acknowledging the stress they feel; providers notice this stress, too, with six Gillette provider interviewees commenting on it. One stakeholder interviewee commented on this aspect of transition planning, noting that mental health care is critical during this phase of a patient and family's journey. A majority (n=9) of Gillette providers interviewed said that it's important to include connections with social work and community resources as part of transition planning.

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**It's just finding those external partners to be able to take that work on. If we had those relationships and those partnerships, then that would be really game changing, as far as I'm concerned. – Gillette provider [referring to connections with adult primary care providers who could see Gillette patients]**

**There is more education that needs to happen with our own providers about transition and the Gillette approach, fostering collaborations between specialty providers and their adult counterparts.**  
**– Gillette provider**

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These families build such strong relationships with their providers. [We need to be] really preparing those families and starting that preparation early...making sure that they feel comfortable and confident with this transition. It's scary leaving someone that you trusted, and you've worked with and built such a strong relationship. And then, all of a sudden, having to feel like you started over. – *Gillette provider*

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## About the prioritization process

In September 2025, Gillette's CHNA team reviewed the key findings and identified health issues to determine which should be elevated as priority health needs. During this prioritization process, the team considered the following questions:

- 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 area?
- 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 and include the following:

- Complex Care Parent Advisors
- Complex Care Program
- Finance and Revenue Cycle
- Gillette Family Council
- Information Systems
- Legal and Compliance
- Marketing and Communications
- Medical Leadership and Providers
- Nurse Care Managers
- Nursing
- Patient Navigators
- Performance Management Strategy Office
- Referral Management Center and Patient Engagement Specialists
- Social Workers
- Transition Committee

# Update on 2022 assessment results and activities

## 2025 Update - 2022 Priority Health Topics - Care Delivery & Coordination

| Health Topic Initiative       | Implementation Strategies  | Gillette Resources  | 2025 Updates  |
|-------------------------------|--|---|---|
| <i>Access to Virtual Care</i> | <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"> <li>• 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.</li> <li>• Assess virtual services in Greater MN</li> <li>• Implement virtual second opinion program</li> <li>• Expand Virtual Pediatric Expert Consults</li> </ul> <p>Rehabilitation Therapies:</p> <ul style="list-style-type: none"> <li>• Expand Virtual Rehab Therapies regionally, nationally and internationally</li> <li>• Develop digital applications to deliver synchronous and asynchronous rehab care. Examples: Asynchronous Speech Therapy and GMA assessment for</li> </ul> | <ul style="list-style-type: none"> <li>-Providers</li> <li>-Nurses</li> <li>-Patient Navigators</li> <li>-Rehab Therapists</li> <li>-IS</li> <li>-Patient Access Specialists</li> <li>-Legal and Compliance</li> <li>-Business Development</li> <li>-Finance</li> <li>-Revenue Cycle</li> </ul> | <p>Gillette successfully implemented virtual care visits across multiple clinic settings where appropriate and in accordance with compliance regulations.</p> <p>The Pediatric Expert Consult (PEC) is a virtual service initially launched in 2021. The PEC is intended to offer consultation to families and assist them in navigating their child's complex medical care needs.</p> <p>To support the expansion of this service, Gillette designated a patient navigation team integrated into the service to ensure successful scheduling of complex needs.</p> <p>Similar to the PEC, the virtual second opinion service is offered via an online form or connecting directly with nursing staff via phone.</p> <p>Marketing and online SEC data demonstrate that these services have significant interest, and appointment requests from online campaigns are among the highest. Gillette marketing and business development teams continue to promote the virtual PEC and second opinion services to our patient and family community, and data indicates volumes are steadily increasing.</p> <p>In addition to these two services, most of our specialty clinics have integrated virtual visits into their scheduling templates to varying degrees, according to their state licensure and scope of practice. We continue to build upon this foundation.</p> <p>We have successfully piloted asynchronous virtual care/telehealth (aka store-and-forward). The Rehab Therapies team is expanding from a pilot to broader deployment of asynchronous virtual care in the fourth quarter of 2025, offering training to all Gillette therapists in the Rehab Therapies department.</p> <p>Clinical areas with notable adoption of virtual services include, but are not limited to, the following clinics/services:</p> <ul style="list-style-type: none"> <li>• Sleep Medicine</li> <li>• Integrated Palliative Care</li> <li>• Neurology/NM</li> <li>• Orthopedics/Spine</li> <li>• Complex Pediatrics</li> <li>• Plastics</li> </ul> |

## 2025 Update - 2022 Priority Health Topics - Care Delivery & Coordination

| Health Topic Initiative | Implementation Strategies   | Gillette Resources   | 2025 Updates   |
|-------------------------|---|--|--|
|                         | <p>early detection of CP</p> <p>In addition, we plan to:</p> <ul style="list-style-type: none"> <li>Implement Virtual Joint Seating Evaluation in Greater MN</li> <li>Develop Gait app to help provide gait services to remote patients</li> </ul>  |  | <ul style="list-style-type: none"> <li>PM&amp;R</li> <li>Rehab Therapies</li> </ul> <p>Gillette continues to evaluate opportunities to improve access to virtual care and leverage existing and new technologies to streamline care, particularly in Greater MN/rural settings.</p>  |
| Care Coordination       | <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 &amp; 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"> <li>- Nurse Care Managers</li> <li>- Patient Navigators</li> <li>- Social Workers</li> <li>- Complex Care Program</li> <li>- Down syndrome Program</li> <li>- Complex Care Parent Advisors</li> <li>- IS</li> <li>- CP Institute</li> </ul> | <p>The Gillette Care Coordination program, launched in 2015, continues to expand and integrate input from multiple disciplines, including social work and scheduling.</p> <p>Gillette Nursing and IS teams developed patient registries for Complex Care, Cerebral Palsy, and Down Syndrome programs. These registries combine automated EHR data with manually entered information from nurse care managers to help actively manage patient risk and care planning.</p> <p>Gillette is also collaborating with technology and EHR vendors to enhance a complex care pediatric registry. The program's primary goal is to improve access, reduce fragmentation, and enhance quality of care for children with medical complexity. Each patient is supported by an integrated, multidisciplinary team—nurse care managers, social work, and patient navigators—who partner with families and providers to ensure timely, coordinated care. Evaluation measures include parent-reported outcomes, health care utilization and access, staff time studies, staff experience, and adherence to care pathways.</p> <p>A formal partnership with the Down Syndrome Association of Minnesota embeds the group in our Down Syndrome Clinic and supports continued program development.</p> <p>A 12-month pre- and post-enrollment sample from the CP Care Coordination program showed:</p> <ul style="list-style-type: none"> <li>Increased positive responses across all parent-reported outcome domains</li> <li>Fewer unmet medical and social needs</li> <li>40% more new outpatient medical appointments</li> <li>39% fewer inpatient hospitalizations</li> <li>16% increase in hip surveillance pathway adherence</li> </ul> |

## 2025 Update - 2022 Priority Health Topics - Care Delivery & Coordination

| Health Topic Initiative                | Implementation Strategies  | Gillette Resources  | 2025 Updates  |
|--|--|---|---|
|  |  |   | <ul style="list-style-type: none"> <li>14% decrease in no-show rates</li> </ul>   |
| <i>Support for resource navigation</i> | <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"> <li>-Social Workers</li> <li>-Care Managers</li> <li>-Gillette clinical team members</li> <li>-Marketing and Communications</li> <li>-Gillette External Website</li> <li>-Identified external organizations dedicated to mental health education and resource identification (e.g., NAMI)</li> </ul> | <p>Gillette developed a comprehensive list of mental health resources and published it on the Gillette website (<a href="#">Gillette Children's Parent Resources and Support</a>) for families and providers to access for free. The list is comprised of a wide variety of resources available locally and nationally.</p> <p>Details, links and other materials are reviewed by MarComm in partnership with social work, the Director of Child and Family Services, and Patient Education to revise and update on a timely basis. Review cadence varies but is actively reviewed by MarComm with regularly to ensure resource links are active.</p> <p>Families receive a link on the confirmation screen of the E-Reg notification that says "Learn more about your visit" that brings them to the external website. The website contains links to information on these and other resources and assistance available.</p> <p>Gillette is dedicated to building new relationships with family support and advocacy groups to expand upon our mission.</p> |
| <i>Transition Planning</i>             | <p>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. Including partnerships with Social Work and Nurse Care Manager with families to transition patients to the</p>  | <ul style="list-style-type: none"> <li>-Transition Workgroup</li> <li>-Transition Task Force</li> <li>-Complex Care Program</li> </ul>  | <p>The Pediatric to Adult Healthcare Transition Initiative officially launched in November 2024, following 18 months of careful and extensive planning to ensure the Healthcare Transition (HCT) program's implementation was comprehensive and robust enough to support patients' care journeys over time. It is crucial to address the complex and fragile needs of our patients and their families when transitioning from pediatric to adult healthcare services, to sustain the achievements made and maintain optimal functioning. The initiative is comprised of the following main components:</p> <p><b>Patient and Family Education</b> a. Resources were published to help support patients and families as they navigate the transition to adulthood on the <a href="https://www.gillettechildrens.org/conditions-care/transition-services">https://www.gillettechildrens.org/conditions-care/transition-services</a> page. All subpages were updated with the most relevant information, and a large group of stakeholders,</p>                |

## 2025 Update - 2022 Priority Health Topics - Care Delivery & Coordination

| Health Topic Initiative | Implementation Strategies   | Gillette Resources   | 2025 Updates   |
|-------------------------|---|--|--|
|                         | <p>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> | <p>-Complex Care Parent Advisors</p> <p>-Down Syndrome Program</p> <p>-Pediatric &amp; Adult Spina Bifida Coordinated Clinic Teams</p> <p>-Nurse Care Managers</p> <p>-Social Work</p> | <p>including Lived Experience Partners, was consulted to ensure that the materials developed were proficient, engaging, and resourceful.</p> <p>b. The Gillette Children's Commitment to Successful Transition to Adult Care was developed and published for patients and families to reference as they work to understand and create a plan for legal decisions that must be made as the patient ages.</p> <p>c. The Transition to Adult Care Milestones at Gillette was developed and published for parents and families to review critical age-related milestones at Gillette and prepare for them ahead of time. d. Standardizing HCT education broadly also enables Gillette staff to share a clear and concise message regarding HCT with patients and families. This results in less confusion, increased patient satisfaction over time, and increased transparency.</p> <p><b>Transition Readiness Assessment</b> a. The Transition Readiness Assessment (TRA) is given to patients in the Spina Bifida Peds and Adult, Down Syndrome, and Complex Care Clinics beginning at age 15 until 24 years of age. Since its implementation in November 2024, it has helped Gillette care teams understand how comfortable patients are with managing their own health and healthcare needs. b. The EMR was enhanced to allow for electronic delivery of the TRA, and a new mPage component was developed to view TRA results in a seamless manner within Oracle. c. In August 2024, a Focus Group was conducted within the Spina Bifida clinic to gain feedback from youth/young adults and parents who had completed the TRA regarding the value of completing the assessment. All those who attended the focus groups agreed that the TRA was a valuable tool, helping to kick-start conversations regarding HCT.</p> <p><b>Clinical Education and Standardized Workflows</b> a. The Pediatric to Adult Health Care Transition process has been implemented initially in four clinics (Spina Bifida Peds and Adult Coordinated Clinics, Down Syndrome, and Complex Care Clinics). When implementing the process, a robust and customized plan is in place prior to kick-off. The initiative team will work with the provider and nursing leaders to ensure that education regarding the process is communicated in various ways, including multiple staff meetings and lunch-and-learns. b. Gillette-wide education has also been provided regarding HCT and the initiative via a Grand Rounds forum in August of 2025.</p> <p><b>Partnerships with External Adult Systems</b> a. Gillette has had initial conversations with HealthPartners' primary care services, performed a strategic partnership analysis of healthcare transition practices funded through the Minnesota Department of Health (MDH), with advocacy, state and professional organizations, and led a discussion with</p> |

## 2025 Update - 2022 Priority Health Topics - Care Delivery & Coordination

| Health Topic Initiative | Implementation Strategies | Gillette Resources | 2025 Updates  |
|-------------------------|---------------------------|--------------------|---|
|                         |                           |                    | <p>the MDH Health Care Home Primary Care Stakeholders group.</p> <p><b>Dissemination of Gillette’s HCT Work</b> a. Held an educational session at the 2025 American Academy for Cerebral Palsy and Developmental Medicine annual meeting and discussed the impact of “Building Resiliency Within a Pediatric to Adult HealthCare Transition (HCT) Program to Support Youth and Young Adults with Childhood-Onset Disability “. b. Presented work at the National 2025 Healthcare Transition Research Consortium Conference and discussed the findings of “Specialty-Care Process Improvement Initiative to Support Youth and Young Adults with Childhood-Onset Disability During the Transition from Pediatric to Adult Care”. c. Presented the HCT work done by Gillette at the 2025 MDH Health Care Home webinar.</p> <p><b>External Grant Funding</b> a. Have secured \$309,000 through 2027 to support Minnesota statewide transition education and facilitate collaboration with community partners.</p> <p><b>Outcomes and Program Monitoring</b> a. Since implementation in November of 2024, we have been monitoring program outcomes to ensure that key metrics are met and maintained as we implement the process in additional clinics. b. Dashboards have been created and published utilizing Power BI and the Enterprise Data Warehouse to help monitor the completion of TRAs and forecast expansion volumes as we look to expand the program's reach. c. Since implementation, we have recorded 84 completed Transition Readiness Assessments and are in the process of conducting chart reviews to ensure documentation of HCT is consistent with the standard process. Over the next six months, an estimated 200 or more appointments are expected to qualify for the HCT process.</p> |



# 2025 implementation plan

| Priority Health Topic  | Implementation Strategies   | Gillette Resources  |
|--|---|---|
| <i>Access to Pediatric Specialty Care and Services</i>       | <p>National and local market projections indicate that access to specialty care for children is increasingly limited for both families and primary care providers. Gillette serves a unique niche in pediatric specialty care and recognizes the important role we play in the health outcomes of some of the most complex pediatric care in the community. The strategies planned or under consideration for implementation are intended to reach a variety of stakeholders to open access from multiple directions, are listed below:</p> <p><u>Providers</u></p> <ul style="list-style-type: none"> <li>Establish a dedicated provider (peer to peer) referral/consult line for external/community providers to reach Gillette specialists. Service offers timely access to clinical collaboration for referring providers.</li> <li>Develop referral relationships with external healthcare systems for continuity and coordination of care across services, especially for patients who require multiple providers across different systems. These relationships will promote efficient clinical information exchange and include a formal plan for bi-directional communication among care coordination teams to monitor progress toward goals.</li> <li>Evaluate Gillette scope of services for opportunities to revise scope and integrate care pathways across clinics and service areas.</li> </ul> <p><u>Patients and Families</u></p> <ul style="list-style-type: none"> <li>Expand the Pediatric Expert Consult (PEC) service, allowing families to schedule time with Gillette specialists to review questions or concerns about their child's condition or development. A marketing awareness plan will be incorporated into the expansion plan.</li> <li>Continue to assess opportunities to expand virtual care offerings and other technologies to remove barriers.</li> </ul> <p><u>Specialty Expansion</u></p> <ul style="list-style-type: none"> <li>Assess capacity and plan for targeted expansion of selected specialties such as genetics, neurology, neurosurgery including Epilepsy care, rehab services, psychiatry.</li> </ul> | <ul style="list-style-type: none"> <li>- Medical Leadership/Gillette Providers</li> <li>- Nursing</li> <li>- Patient Navigators</li> <li>- PMSO/IS</li> <li>- RMCP/Patient Access Specialists</li> <li>- Legal and Compliance</li> <li>- Strategic Business Development</li> <li>- Finance/Revenue Cycle</li> </ul> |
| <i>Caregiver Support and Support for Resource Navigation</i> | <p>We recognize that the highly complex nature of the patient population served at Gillette can be stressful for families to manage, especially since many of our families have limited resources. It is our goal to actively guide family systems to resources within Gillette and the surrounding community to achieve the most positive outcomes for our patients.</p> <ul style="list-style-type: none"> <li>Recruit a Provider Community Referral Liaison to develop relationships with patient- and family-facing community organizations and educate the community about Gillette specialty care and our unique culture.</li> <li>Expand social media opportunities for patient communities to connect online, share personal experiences, and provide group support, reaching broader audiences including complex pediatrics, rare diseases, and</li> </ul>   | <ul style="list-style-type: none"> <li>- Strategic Business Development</li> <li>- Nurse Care Managers</li> <li>- Patient Navigators</li> <li>- Social Workers</li> <li>- Complex Care Program</li> <li>- Complex Care Parent Advisors</li> <li>- PMSO/IS</li> </ul>  |

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| Priority Health Topic  | Implementation Strategies   | Gillette Resources  |
|--|---|---|
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# Appendix

## A. 2025 CHNA CAREGIVER SURVEY DATA TABLES

Some percentages may not add up to 100% due to rounding.

### A1. Has someone at Gillette talked with you about your child's transition to adult care? (N=116)

|          | N  | %   |
|----------|----|-----|
| Yes      | 23 | 20% |
| No       | 85 | 73% |
| Not sure | 8  | 7%  |

Note: This question was asked to those with a child over age 16.

### A2. Was it your physician that had conversations with you about the transition to adult care? (N=22)

|          | N  | %   |
|----------|----|-----|
| Yes      | 15 | 68% |
| No       | 4  | 18% |
| Not sure | 3  | 14% |

Note: This question was asked to those who responded "Yes" to Q5.

### A3. Was it clear to you when the transition to adult care should take place? (N=1,120)

|          | N   | %   |
|----------|-----|-----|
| Yes      | 447 | 40% |
| No       | 357 | 32% |
| Not sure | 316 | 28% |

### A4. Has your child seen a genetic counselor? (N=1,113)

|                     | N   | %   |
|---------------------|-----|-----|
| Yes, at Gillette    | 119 | 11% |
| Yes, somewhere else | 187 | 17% |
| No                  | 762 | 68% |
| Not sure            | 45  | 4%  |

### A5. Has your child received either of the following services? (Check all that apply) (N=302)

|                           | N   | %   |
|---------------------------|-----|-----|
| Genetic testing           | 257 | 85% |
| Meeting with a geneticist | 208 | 69% |
| Something else            | 22  | 7%  |
| Neither of these          | 17  | 6%  |

Note: This question was asked to those who responded “Yes” to Q8.

**A6. Did the results of testing change the course of your child’s care? (N=252)**

|            | N   | %   |
|------------|-----|-----|
| Yes        | 90  | 36% |
| No         | 150 | 60% |
| Don’t know | 12  | 5%  |

Note: This question was asked to those who indicated that their child has received genetic testing.

**A7. Are you interested in learning about any gene therapy trials that could benefit your child? (N=1,100)**

|          | N   | %   |
|----------|-----|-----|
| Yes      | 297 | 27% |
| No       | 561 | 51% |
| Not sure | 242 | 22% |

**A8. Has your child seen a psychiatrist (MD) in the past 24 months? (N=1,091)**

|          | N   | %   |
|----------|-----|-----|
| Yes      | 174 | 16% |
| No       | 885 | 81% |
| Not sure | 32  | 3%  |

**A9. Has your child needed emergency services in the past 12 months? (N=1,090)**

|                     | N   | %   |
|---------------------|-----|-----|
| Yes, once           | 193 | 18% |
| Yes, more than once | 84  | 8%  |
| No                  | 805 | 74% |
| Not sure            | 8   | 1%  |

**A10. Did you inform the emergency team that your child is a Gillette patient? (N=267)**

|     | N   | %   |
|-----|-----|-----|
| Yes | 109 | 41% |

|          |     |     |
|----------|-----|-----|
| No       | 137 | 51% |
| Not sure | 21  | 8%  |

Note: This question was asked to those who responded “Yes” to Q14.

**A11. Following emergency care, was your child admitted to a hospital? (N=267)**

|          | N   | %   |
|----------|-----|-----|
| Yes      | 110 | 41% |
| No       | 156 | 58% |
| Not sure | 1   | <1% |

Note: This question was asked to those who responded “Yes” to Q14.

**A12. Did you request that your child be transferred to Gillette? (N=108)**

|                                    | N  | %   |
|------------------------------------|----|-----|
| Yes, and they were transferred     | 24 | 22% |
| Yes, but they were not transferred | 3  | 3%  |
| No                                 | 58 | 54% |
| I did not know this was an option  | 22 | 20% |
| Not sure                           | 1  | 1%  |

Note: This question was asked to those who responded “Yes” to Q18.

**A13. I understand the components of my care plan. (N=992)**

|                   | N   | %   |
|-------------------|-----|-----|
| Strongly agree    | 651 | 66% |
| Somewhat agree    | 268 | 27% |
| Somewhat disagree | 39  | 4%  |
| Strongly disagree | 34  | 3%  |

**A14. I know what to expect next with my child’s care at Gillette. (N=1,005)**

|                   | N   | %   |
|-------------------|-----|-----|
| Strongly agree    | 670 | 67% |
| Somewhat agree    | 265 | 26% |
| Somewhat disagree | 39  | 4%  |
| Strongly disagree | 31  | 3%  |

**A15. If I have questions about the care plan, I know who to contact. (N=996)**

|                | N   | %   |
|----------------|-----|-----|
| Strongly agree | 662 | 67% |

|                   |     |     |
|-------------------|-----|-----|
| Somewhat agree    | 224 | 23% |
| Somewhat disagree | 58  | 6%  |
| Strongly disagree | 52  | 5%  |

**A16. It is easy to reach my care team. (N=975)**

|                   | <b>N</b> | <b>%</b> |
|-------------------|----------|----------|
| Strongly agree    | 569      | 58%      |
| Somewhat agree    | 302      | 31%      |
| Somewhat disagree | 73       | 8%       |
| Strongly disagree | 31       | 3%       |

**A17. Following a visit with Gillette, do you know how to access your visit summary (which may include care instructions)? (N=1,024)**

|          | <b>N</b> | <b>%</b> |
|----------|----------|----------|
| Yes      | 870      | 85%      |
| No       | 117      | 11%      |
| Not sure | 37       | 4%       |

**A18. Has your child had an inpatient stay at Gillette within the past year? (N=1,026)**

|          | <b>N</b> | <b>%</b> |
|----------|----------|----------|
| Yes      | 209      | 20%      |
| No       | 811      | 79%      |
| Not sure | 6        | 1%       |

**A19. Did you feel that Gillette staff adequately prepared you for your child's inpatient stay? (N=200)**

|     | <b>N</b> | <b>%</b> |
|-----|----------|----------|
| Yes | 188      | 94%      |
| No  | 12       | 6%       |

Note: This question was asked to those who responded "Yes" to Q23.



**A20. Did you feel that Gillette staff adequately prepared you for discharge? (N=202)**

|     | N   | %   |
|-----|-----|-----|
| Yes | 191 | 95% |
| No  | 11  | 5%  |

Note: This question was asked to those who responded “Yes” to Q23.

**A21. Did you receive a follow-up call within 48 hours of discharge? (N=208)**

|                             | N   | %   |
|-----------------------------|-----|-----|
| Yes, it was helpful         | 160 | 77% |
| Yes, but it was not helpful | 16  | 8%  |
| No, I didn’t receive a call | 10  | 5%  |
| Don’t know                  | 22  | 11% |

Note: This question was asked to those who responded “Yes” to Q23.

**A22. If multiple appointments at Gillette were needed (e.g., testing and/or provider visits), how easy or difficult was it for you to schedule all services to occur on the same day? (N=821)**

|                    | N   | %   |
|--------------------|-----|-----|
| Very easy          | 419 | 51% |
| Somewhat easy      | 266 | 32% |
| Somewhat difficult | 86  | 11% |
| Very difficult     | 50  | 6%  |

**A23. If testing or medical records were needed before an appointment with Gillette, were your records received in time? (N=640)**

|   | N   | %   |
|---|-----|-----|
| Yes, all records were received in time for the appointment    | 603 | 94% |
| No, not all records were received in time for the appointment | 37  | 6%  |

**A24. Gillette offers a Pediatric Expert Phone Consultation for families with new or unknown diagnoses, who are not current Gillette patients. Would you have found this service valuable before you came to Gillette? (N=1,009)**

|            | N   | %   |
|------------|-----|-----|
| Yes        | 500 | 50% |
| No         | 193 | 19% |
| Don’t know | 316 | 31% |

**A25. Gillette is considering offering patient education videos. Which of the following would you be interested in? (Check all that apply) (N=1,008)**

|  | <b>N</b> | <b>%</b> |
|--|----------|----------|
| What to expect on your care journey              | 535      | 53%      |
| Information about follow-up care from procedures | 508      | 50%      |
| Other  | 35       | 4%       |
| I would not be interested in this                | 314      | 31%      |

**A26. In the past year, what things have caused frustration when accessing services at Gillette? (Check all that apply) (N=973)**

|   | <b>N</b> | <b>%</b> |
|---|----------|----------|
| Appointment availability with preferred provider(s)   | 248      | 26%      |
| Reaching Gillette schedulers (for example, waiting on hold and/or not getting to the right person)  | 173      | 18%      |
| Waiting for call back/follow-up from Gillette schedulers  | 123      | 13%      |
| Getting help with coordinating multiple appointments on the same day  | 111      | 11%      |
| Getting add-on appointments or services scheduled the same day as an existing appointment (such as the ability to access diagnostic tests while you are at Gillette for an appointment) | 66       | 7%       |
| Receiving interpreter services when needed  | 2        | <1%      |
| Other   | 121      | 12%      |
| I have not experienced any frustration when accessing services at Gillette in the past year   | 513      | 53%      |
| Don't know  | 29       | 3%       |

**A27. Of the following services provided by Gillette, which were you aware of? (Check all that apply) (N=996)**

|   | <b>N</b> | <b>%</b> |
|---|----------|----------|
| Down Syndrome Clinic  | 93       | 9%       |
| Developmental Evaluation (identification of developmental delays)   | 218      | 22%      |
| Pediatric Expert Consult (support and plans regarding complex conditions for new patients)                      | 222      | 22%      |
| Urgent care for general medical conditions for current Gillette patients (also called "Quick Care")             | 231      | 23%      |
| Acute orthopedic clinic (i.e., urgent care for orthopedic services), open to Gillette and non-Gillette patients | 337      | 34%      |
| Rehabilitation therapy services (i.e., physical therapy, speech language pathology, occupational therapy)       | 601      | 60%      |

|                   |     |     |
|-------------------|-----|-----|
| None of the above | 227 | 23% |
|-------------------|-----|-----|

**A28. Have you used any of these services at Gillette? (Check all that apply) (N=985)**

|   | N   | %   |
|---|-----|-----|
| Down Syndrome Clinic  | 6   | 1%  |
| Developmental Evaluation (identification of developmental delays)   | 86  | 9%  |
| Pediatric Expert Consult (support and plans regarding complex conditions for new patients)                      | 97  | 10% |
| Urgent care for general medical conditions for current Gillette patients (also called "Quick Care")             | 59  | 6%  |
| Acute orthopedic clinic (i.e., urgent care for orthopedic services), open to Gillette and non-Gillette patients | 150 | 15% |
| Rehabilitation therapy services (i.e., physical therapy, speech language pathology, occupational therapy)       | 383 | 39% |
| None of the above   | 435 | 44% |

**A29. How well did the Down Syndrome Clinic services meet your needs? (N=6)**

|               | N |
|---------------|---|
| Very well     | 5 |
| Somewhat well | 1 |
| Not very well | 0 |
| Not sure      | 0 |

Note: This question was asked to those who reported having used the Down Syndrome Clinic. Percentages are not reported due to the small N.

**A30. How well did the Developmental Evaluation services meet your needs? (N=85)**

|               | N  | %   |
|---------------|----|-----|
| Very well     | 61 | 72% |
| Somewhat well | 20 | 24% |
| Not very well | 1  | 1%  |
| Not sure      | 3  | 4%  |

Note: This question was asked to those who reported having used the Developmental Evaluation services.

**A31. How well did the Pediatric Expert Consult services meet your needs? (N=97)**

|               | N  | %   |
|---------------|----|-----|
| Very well     | 76 | 78% |
| Somewhat well | 17 | 18% |
| Not very well | 1  | 1%  |
| Not sure      | 3  | 3%  |

Note: This question was asked to those who reported having used the Pediatric Expert Consult services.

**A32. How well did the Urgent care for general medical conditions for current Gillette patients services meet your needs? (N=59)**

|               | N  | %   |
|---------------|----|-----|
| Very well     | 50 | 85% |
| Somewhat well | 7  | 12% |
| Not very well | 1  | 2%  |
| Not sure      | 1  | 2%  |

Note: This question was asked to those who reported having used the Urgent care for general medical conditions for current Gillette patients.

**A33. How well did the Acute orthopedic clinic services meet your needs? (N=148)**

|               | N   | %   |
|---------------|-----|-----|
| Very well     | 117 | 79% |
| Somewhat well | 23  | 16% |
| Not very well | 6   | 4%  |
| Not sure      | 2   | 1%  |

Note: This question was asked to those who reported having used the Acute orthopedic clinic services.

**A34. How well did the Rehabilitation therapy services meet your needs? (N=382)**

|               | N   | %   |
|---------------|-----|-----|
| Very well     | 288 | 75% |
| Somewhat well | 73  | 19% |
| Not very well | 18  | 5%  |
| Not sure      | 3   | 1%  |

Note: This question was asked to those who reported having used the Rehabilitation therapy services.

**A35. Please indicate how well you feel Gillette embodies the following values: In every encounter, Gillette begins with compassion, generosity and an open heart and mind. (N=983)**

|               | N   | %   |
|---------------|-----|-----|
| Very well     | 787 | 80% |
| Somewhat well | 169 | 17% |
| Not very well | 27  | 3%  |

**A36. Please indicate how well you feel Gillette embodies the following values: Gillette works to understand the whole story, understanding that inclusivity grows our empathy, diversity fuels our creativity, and equity unites us. (N=955)**

|               | N   | %   |
|---------------|-----|-----|
| Very well     | 749 | 78% |
| Somewhat well | 167 | 18% |
| Not very well | 39  | 4%  |

**A37. Please indicate how well you feel Gillette embodies the following values: Gillette helps patients realize their dreams as they each create their own story. (N=881)**

|               | N   | %   |
|---------------|-----|-----|
| Very well     | 657 | 75% |
| Somewhat well | 185 | 21% |
| Not very well | 39  | 4%  |

**A38. Please indicate how well you feel Gillette embodies the following values: Gillette is continuously working to innovate and improve. They are committed to creating a global community of care, equity and opportunity. (N=888)**

|               | N   | %   |
|---------------|-----|-----|
| Very well     | 693 | 78% |
| Somewhat well | 169 | 19% |
| Not very well | 26  | 3%  |

## B. 2025 CHNA ADULT PATIENT SURVEY DATA TABLES

Some percentages may not add up to 100% due to rounding.

### B1. Has someone at Gillette talked with you about your transition to adult care? (N=304)

|          | N   | %   |
|----------|-----|-----|
| Yes      | 168 | 55% |
| No       | 110 | 36% |
| Not sure | 26  | 9%  |

### B2. Was it your physician that had conversations with you about the transition to adult care? (N=161)

|          | N   | %   |
|----------|-----|-----|
| Yes      | 123 | 76% |
| No       | 19  | 12% |
| Not sure | 19  | 12% |

Note: This question was asked to those who responded “Yes” to Q5.

### B3. Was it clear to you when the transition to adult care should take place? (N=282)

|          | N   | %   |
|----------|-----|-----|
| Yes      | 152 | 54% |
| No       | 82  | 29% |
| Not sure | 48  | 17% |

### B4. Have you seen a psychiatrist (MD) in the past 24 months? (N=280)

|          | N   | %   |
|----------|-----|-----|
| Yes      | 71  | 25% |
| No       | 195 | 70% |
| Not sure | 14  | 5%  |

### B5. I understand the components of my care plan. (N=248)

|                   | N   | %   |
|-------------------|-----|-----|
| Strongly agree    | 147 | 59% |
| Somewhat agree    | 68  | 27% |
| Somewhat disagree | 17  | 7%  |
| Strongly disagree | 16  | 7%  |

**B6. I know what to expect next with my care at Gillette. (N=261)**

|                   | N   | %   |
|-------------------|-----|-----|
| Strongly agree    | 157 | 60% |
| Somewhat agree    | 78  | 30% |
| Somewhat disagree | 16  | 6%  |
| Strongly disagree | 10  | 4%  |

**B7. If I have questions about the care plan, I know who to contact. (N=251)**

|                   | N   | %   |
|-------------------|-----|-----|
| Strongly agree    | 156 | 62% |
| Somewhat agree    | 56  | 22% |
| Somewhat disagree | 22  | 9%  |
| Strongly disagree | 17  | 7%  |

**B8. It is easy to reach my care team. (N=261)**

|                   | N   | %   |
|-------------------|-----|-----|
| Strongly agree    | 147 | 56% |
| Somewhat agree    | 83  | 32% |
| Somewhat disagree | 18  | 7%  |
| Strongly disagree | 13  | 5%  |

**B9. Following a visit with Gillette, do you know how to access your visit summary (which may include care instructions)? (N=259)**

|          | N   | %   |
|----------|-----|-----|
| Yes      | 215 | 83% |
| No       | 24  | 9%  |
| Not sure | 20  | 8%  |

**B10. Have you had an inpatient stay at Gillette within the past year? (N=258)**

|          | N   | %   |
|----------|-----|-----|
| Yes      | 27  | 11% |
| No       | 228 | 88% |
| Not sure | 3   | 1%  |

**B11. Did you feel that Gillette staff adequately prepared you for your inpatient stay? (N=27)**

|     | <b>N</b> | <b>%</b> |
|-----|----------|----------|
| Yes | 26       | 96%      |
| No  | 1        | 4%       |

Note: This question was asked to those who responded “Yes” to Q23.

**B12. Did you feel that Gillette staff adequately prepared you for discharge? (N=27)**

|     | <b>N</b> | <b>%</b> |
|-----|----------|----------|
| Yes | 26       | 96%      |
| No  | 1        | 4%       |

Note: This question was asked to those who responded “Yes” to Q23.

**B13. Did you receive a follow-up call within 48 hours of discharge? (N=27)**

|                             | <b>N</b> | <b>%</b> |
|-----------------------------|----------|----------|
| Yes, it was helpful         | 23       | 85%      |
| Yes, but it was not helpful | 1        | 4%       |
| No, I didn’t receive a call | 1        | 4%       |
| Don’t know                  | 2        | 7%       |

Note: This question was asked to those who responded “Yes” to Q23.

**B14. If multiple appointments at Gillette were needed (e.g., testing and/or provider visits), how easy or difficult was it for you to schedule all services to occur on the same day? (N=207)**

|                    | <b>N</b> | <b>%</b> |
|--------------------|----------|----------|
| Very easy          | 91       | 44%      |
| Somewhat easy      | 71       | 34%      |
| Somewhat difficult | 28       | 14%      |
| Very difficult     | 17       | 8%       |

**B15. If testing or medical records were needed before an appointment with Gillette, were your records received in time? (N=140)**

|   | <b>N</b> | <b>%</b> |
|---|----------|----------|
| Yes, all records were received in time for the appointment    | 128      | 91%      |
| No, not all records were received in time for the appointment | 12       | 9%       |



**B16. Gillette is considering offering patient education videos. Which of the following would you be interested in? (Check all that apply) (N=255)**

|  | N   | %   |
|--|-----|-----|
| What to expect on your care journey              | 100 | 39% |
| Information about follow-up care from procedures | 110 | 43% |
| Other  | 18  | 7%  |
| I would not be interested in this                | 108 | 42% |

**B17. In the past year, what things have caused frustration when accessing services at Gillette? (Check all that apply) (N=245)**

|   | N   | %   |
|---|-----|-----|
| Appointment availability with preferred provider(s)   | 70  | 29% |
| Reaching Gillette schedulers (for example, waiting on hold and/or not getting to the right person)  | 50  | 20% |
| Waiting for call back/follow-up from Gillette schedulers  | 41  | 17% |
| Getting help with coordinating multiple appointments on the same day  | 33  | 14% |
| Getting add-on appointments or services scheduled the same day as an existing appointment (such as the ability to access diagnostic tests while you are at Gillette for an appointment) | 24  | 10% |
| Receiving interpreter services when needed  | 1   | <1% |
| Other   | 27  | 11% |
| I have not experienced any frustration when accessing services at Gillette in the past year   | 119 | 49% |
| Don't know  | 9   | 4%  |

**B18. Of the following services provided by Gillette, which were you aware of? (Check all that apply) (N=253)**

|   | N   | %   |
|---|-----|-----|
| Down Syndrome Clinic  | 34  | 13% |
| Developmental Evaluation (identification of developmental delays)   | 63  | 25% |
| Pediatric Expert Consult (support and plans regarding complex conditions for new patients)                      | 65  | 26% |
| Urgent care for general medical conditions for current Gillette patients (also called "Quick Care")             | 74  | 29% |
| Acute orthopedic clinic (i.e., urgent care for orthopedic services), open to Gillette and non-Gillette patients | 82  | 32% |
| Rehabilitation therapy services (i.e., physical therapy, speech language pathology, occupational therapy)       | 172 | 68% |

|                   |    |     |
|-------------------|----|-----|
| None of the above | 44 | 17% |
|-------------------|----|-----|

**B19. Have you used any of these services at Gillette? (Check all that apply) (N=251)**

|   | N   | %   |
|---|-----|-----|
| Down Syndrome Clinic  | 7   | 3%  |
| Developmental Evaluation (identification of developmental delays)   | 20  | 8%  |
| Pediatric Expert Consult (support and plans regarding complex conditions for new patients)                      | 34  | 14% |
| Urgent care for general medical conditions for current Gillette patients (also called "Quick Care")             | 29  | 12% |
| Acute orthopedic clinic (i.e., urgent care for orthopedic services), open to Gillette and non-Gillette patients | 38  | 15% |
| Rehabilitation therapy services (i.e., physical therapy, speech language pathology, occupational therapy)       | 135 | 54% |
| None of the above   | 86  | 34% |

**B20. How well did the Down Syndrome Clinic services meet your needs? (N=7)**

|               | N |
|---------------|---|
| Very well     | 6 |
| Somewhat well | 1 |
| Not very well | 0 |
| Not sure      | 0 |

Note: This question was asked to those who reported having used the Down Syndrome Clinic. Percentages are not reported due to the small N.

**B21. How well did the Developmental Evaluation services meet your needs? (N=20)**

|               | N  | %   |
|---------------|----|-----|
| Very well     | 12 | 60% |
| Somewhat well | 5  | 25% |
| Not very well | 1  | 5%  |
| Not sure      | 2  | 10% |

Note: This question was asked to those who reported having used the Developmental Evaluation services.

**B22. How well did the Pediatric Expert Consult services meet your needs? (N=34)**

|               | N  | %   |
|---------------|----|-----|
| Very well     | 25 | 74% |
| Somewhat well | 4  | 12% |
| Not very well | 1  | 3%  |
| Not sure      | 4  | 12% |

Note: This question was asked to those who reported having used the Pediatric Expert Consult services.

**B23. How well did the Urgent care for general medical conditions for current Gillette patients services meet your needs? (N=29)**

|               | N  | %   |
|---------------|----|-----|
| Very well     | 22 | 76% |
| Somewhat well | 4  | 14% |
| Not very well | 2  | 7%  |
| Not sure      | 1  | 3%  |

Note: This question was asked to those who reported having used the Urgent care for general medical conditions for current Gillette patients.

**B24. How well did the Acute orthopedic clinic services meet your needs? (N=38)**

|               | N  | %   |
|---------------|----|-----|
| Very well     | 28 | 74% |
| Somewhat well | 4  | 11% |
| Not very well | 2  | 5%  |
| Not sure      | 4  | 11% |

Note: This question was asked to those who reported having used the Acute orthopedic clinic services.

**B25. How well did the Rehabilitation therapy services meet your needs? (N=134)**

|               | N  | %   |
|---------------|----|-----|
| Very well     | 92 | 69% |
| Somewhat well | 32 | 24% |
| Not very well | 7  | 5%  |
| Not sure      | 3  | 2%  |

Note: This question was asked to those who reported having used the Rehabilitation therapy services.

**B26. Please indicate how well you feel Gillette embodies the following values: In every encounter, Gillette begins with compassion, generosity and an open heart and mind. (N=250)**

|               | N   | %   |
|---------------|-----|-----|
| Very well     | 208 | 83% |
| Somewhat well | 37  | 15% |
| Not very well | 5   | 2%  |

**B27. Please indicate how well you feel Gillette embodies the following values: Gillette works to understand the whole story, understanding that inclusivity grows our empathy, diversity fuels our creativity, and equity unites us. (N=245)**

|               | N   | %   |
|---------------|-----|-----|
| Very well     | 196 | 80% |
| Somewhat well | 42  | 17% |
| Not very well | 7   | 3%  |

**B28. Please indicate how well you feel Gillette embodies the following values: Gillette helps patients realize their dreams as they each create their own story. (N=236)**

|               | N   | %   |
|---------------|-----|-----|
| Very well     | 158 | 67% |
| Somewhat well | 66  | 28% |
| Not very well | 12  | 5%  |

**B29. Please indicate how well you feel Gillette embodies the following values: Gillette is continuously working to innovate and improve. They are committed to creating a global community of care, equity and opportunity. (N=237)**

|               | N   | %   |
|---------------|-----|-----|
| Very well     | 182 | 77% |
| Somewhat well | 46  | 19% |
| Not very well | 9   | 4%  |

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451 Lexington Parkway North  
Saint Paul, Minnesota 55104  
651-280-2700 | [www.wilderresearch.org](http://www.wilderresearch.org)

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