SANFORD Children's

Supporting Children with Medical Complexity

2022
Program Outcomes and Family Perceptions

February 2022

SOUTH DAKOTA DEPARTMENT OF HEALTH

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POPULATION
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Sanford Children's Medically Complex Care Program

In April 2020, Sanford Children's Hospital and Specialty Clinic launched a program called the Sanford Patient Navigation Program for Children with Medical Complexity (CMC). The name has since been changed to the Sanford Children's Medically Complex Care Program. The program started with support from the South Dakota (SD) Department of Health to address the needs of children with medical complexity identified both through pediatric specialty providers' experiences and a statewide survey[1] of families with children with special healthcare needs (CSHCN).

Since inception, the program has employed a Registered Nurse (RN) Patient Navigator who is the point of contact to improve communication among participating families, affiliated professionals, and community support programs. This individual aids families in navigating the complex healthcare system with the goal of improving care. In December 2021, a Nurse Practitioner was added to the staff to better meet the medical needs of the patients. The program priorities include:

1) Coordination of complex care across the healthcare spectrum
2) Navigating medical systems to enhance efficiencies
3) Decreased cost of unnecessary or redundant travel
4) Liaison relationships with local primary care
5) Referrals to community resources and partnerships with schools
6) Leveraging technology to bring forth innovative means to breach the challenge of long distances
7) Creation of safety nets and emergency plans to give families peace of mind and reassurance
8) Assistance with care transitions and financial needs
9) Help in understanding of various aspects of care

The Population Health Evaluation Center at South Dakota State University conducts periodic reviews of the program to assess family satisfaction, provider perceptions and service delivery. This report is one such review. It presents information from two surveys of children's parents/guardians, one done when the family enrolled in the Sanford program and the second done between May and August 2022. Length of time in the program when completing the second survey varied across families from roughly one year to just over two years.

Fifty-six families have enrolled in the program; 15 are no longer enrolled. Of the 41 families still enrolled, 35 completed the follow-up survey, for a response rate of 85.4%. In compiling the survey results presented here, we hope to report on the major changes (or lack of changes) over the length of the program, from the first patients' enrollment to 2022.

Eight of the surveys' findings are of greatest importance, and these will be covered in the first section of this document, the **executive summary.** These findings are: Receiving care in a medical home, awareness of a shared care plan, overall need for extra help, families' specific needs, connection with community resources, impact of children's health on families, and providers' concern for impact on families. The second section will be **recommendations** growing out of the findings. The third and final section will be the **technical report**, containing detailed information on evaluation methods, program participants, survey findings, and caregiver comments. This document will conclude with a **reference list** and the **one-year survey form**.

Receiving Care in a Medical Home

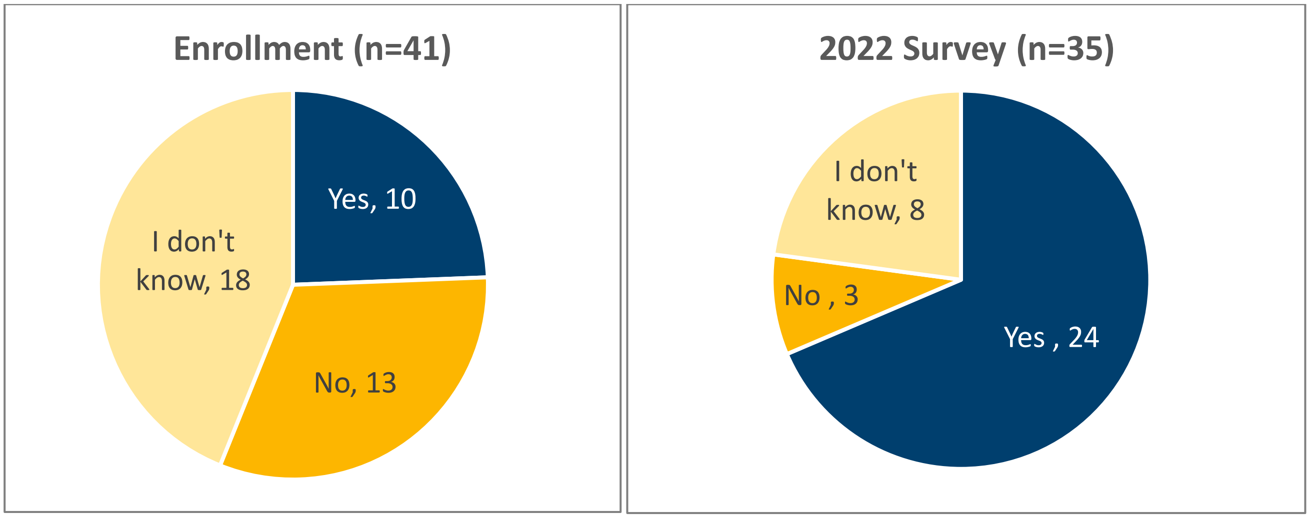
It is important to first consider the care that the children receive at home, before and during their time in the Sanford program. Receipt of care in a "medical home" is a national performance measure developed for children with medical complexity. The five components of receiving care in a "medical home" are: having at least one consistent healthcare provider, a usual place for medical care, the ability to easily receive referrals when needed, effective care coordination, and "family-centered care." "Family-centered care" means having a healthcare team that spends enough time with the child, listens carefully, shows sensitivity to family values, provides specific medical information, and makes parents feel like partners.

Receiving care in a medical home was very low on the enrollment survey, measured at just 14.6% of all families. This indicator improved considerably by 2022 with 25.7% of families reporting their children received care in what qualified as a "medical home." This is an important measure of the quality of a child's care and one that seems to have improved considerably following enrollment in the Sanford program.

Awareness of a Shared Care Plan

Once enrollment in the program has been completed, it is important that a shared plan of care is put into place in a timely way. The care plan is a tool used to document information about a child's health problems, medications, and goals. The plan is used to promote communication among the professionals working with the family. A significant goal of the program is to increase the use of care plans. At the time of enrollment, 18 families did not know if a care plan existed. This number decreased to eight by 2022. Clearly families' knowledge and use of their care plans increased significantly from enrollment to 2022. This suggests, as illustrated in the figure below, that the Sanford program is increasing the involvement of parents in ways that improve the healthcare of their children.

Figure 1. Parental Awareness of Shared Plan of Care



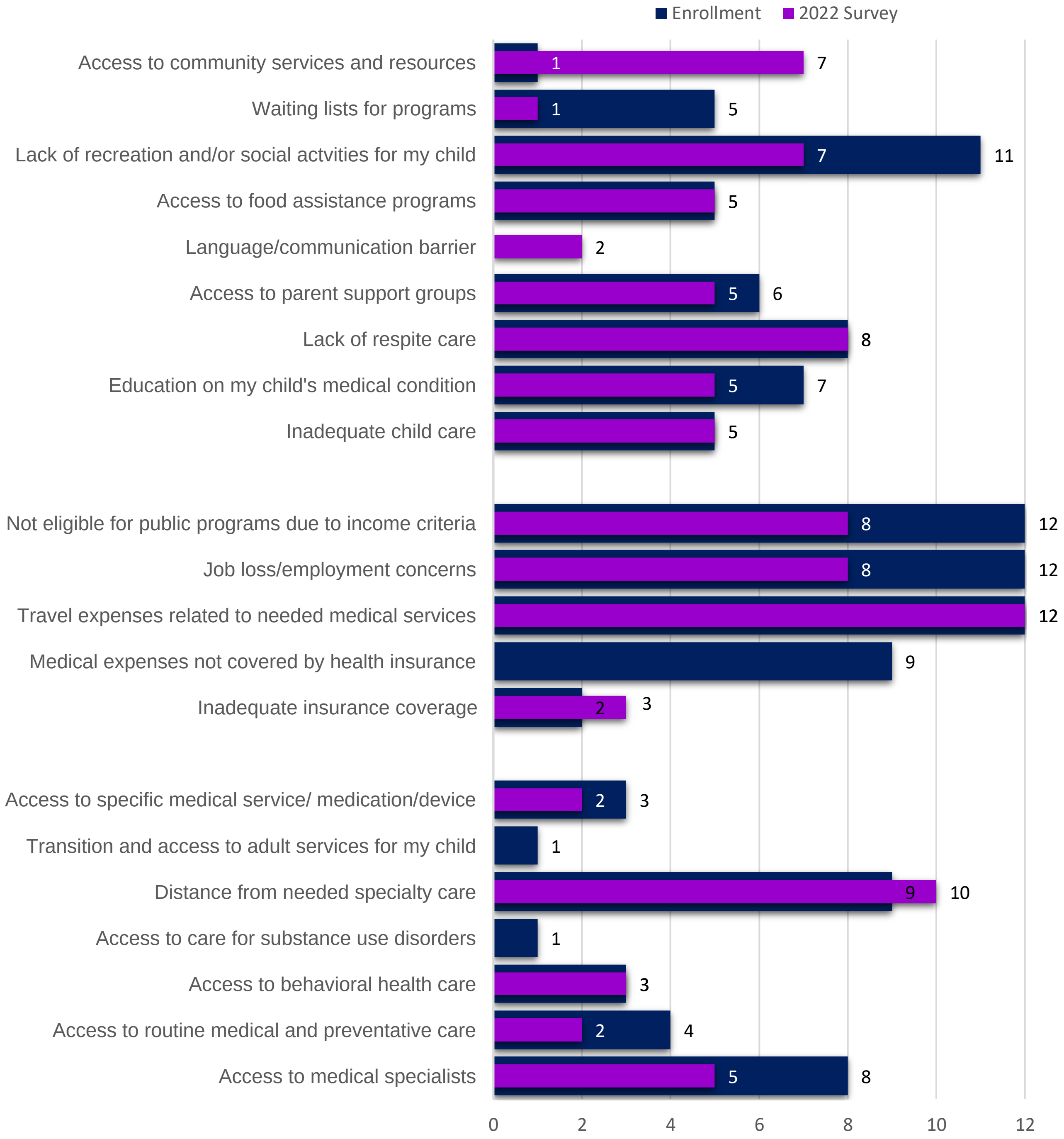
Overall Need for Extra Help

So how often did families feel they were receiving the care they needed for their children? At enrollment, 65.9% of families said they needed more help in caring for their children and did not receive it. By 2022, this rate dropped significantly, to just 40.0% of families who said they did not receive help when they needed it. Similarly, no families reported needing extra help and not receiving it in 2022. This indicates that the Sanford program does provide the help families sometimes need to deal with children with medical complexity.

Families' Specific Needs

Families were asked more specifically about their needs for care at the time of enrollment and at the time of the 2022 survey. Needs were examined in three areas: Community Resources. Financial Concerns, and Medical Care. Results here were mixed, as shown in the chart below. The need for recreational activities, employment assistance, and routine/specialty care were less common concerns in 2022. Lack of access to community resources was more commonly noted in 2022. As a group, fewer families identified needs in the 2022 survey, indicating perhaps that the Sanford program was better addressing unmet needs.

Figure 2. Identified Medical, Financial, and Community Resource Challenges



Connection with Community Resources

This finding expands a bit on what was discussed in the last section. Children with medical complexity and their caregivers often need help that extends far beyond the medical. The survey asked families if the healthcare team helped them to connect with community resources. In 2022, the families served by the program asked for more help with travel expenses, with parental support resources, with direct financial assistance and with transportation to medical appointments than they had as a group at the time of enrollment. But requests for help connecting with other assistance programs such as WIC, Medicaid, Birth to Three, respite care and financial advocacy declined from the families' time of enrollment to 2022.

Impact of Children's Health on Families

The demands on parents caring for children with medical complexity are often overwhelming. Parents are frequently exhausted by being asked to fill in existing care gaps left empty by medical and social support systems.

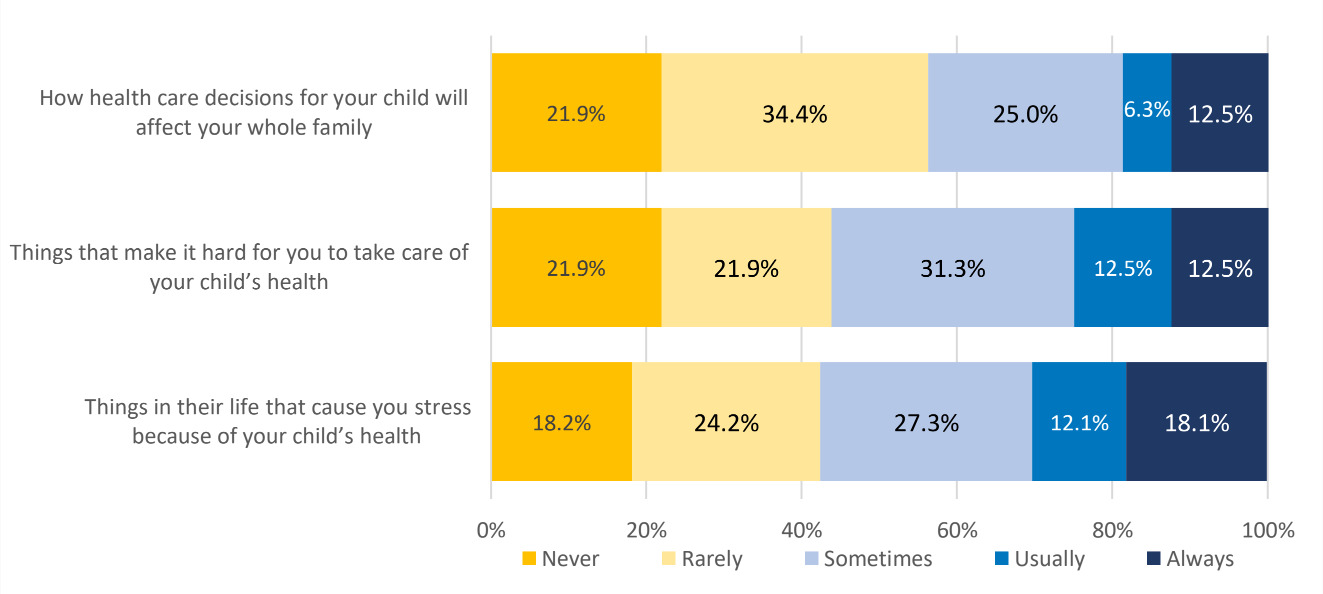
Caregivers of children in the Sanford program were asked to rate on a scale of 1 to 10, how much distress they experienced in a single week before completing the survey. The number 1 indicated "no distress." The number 10 indicated "extreme distress." While levels of distress among caregivers remained high, levels did drop collectively from 5.1 at enrollment to 4.4 at the 2022 survey point.

Providers' Concern for Impact on Families

Clearly the well-being of parents affects their ability to care for their children with medical complexity. The enrollment survey had a single question on providers' concern as to how the child's medical condition affects the family. The question was: "I have been asked by my child's healthcare team how my child's condition affects our family (e.g., the impact on siblings, the time my child's care takes, lost sleep, extra expenses, etc.)." Seventy percent of the respondents answered "no."

On the 2022 survey, questions were added on providers asking about "things that make it hard for you to take care of your child's health" and "things in their life that cause you stress because of your child's health." The 2022 responses are shown below.

Figure 3. Providers' Questions to Caregivers



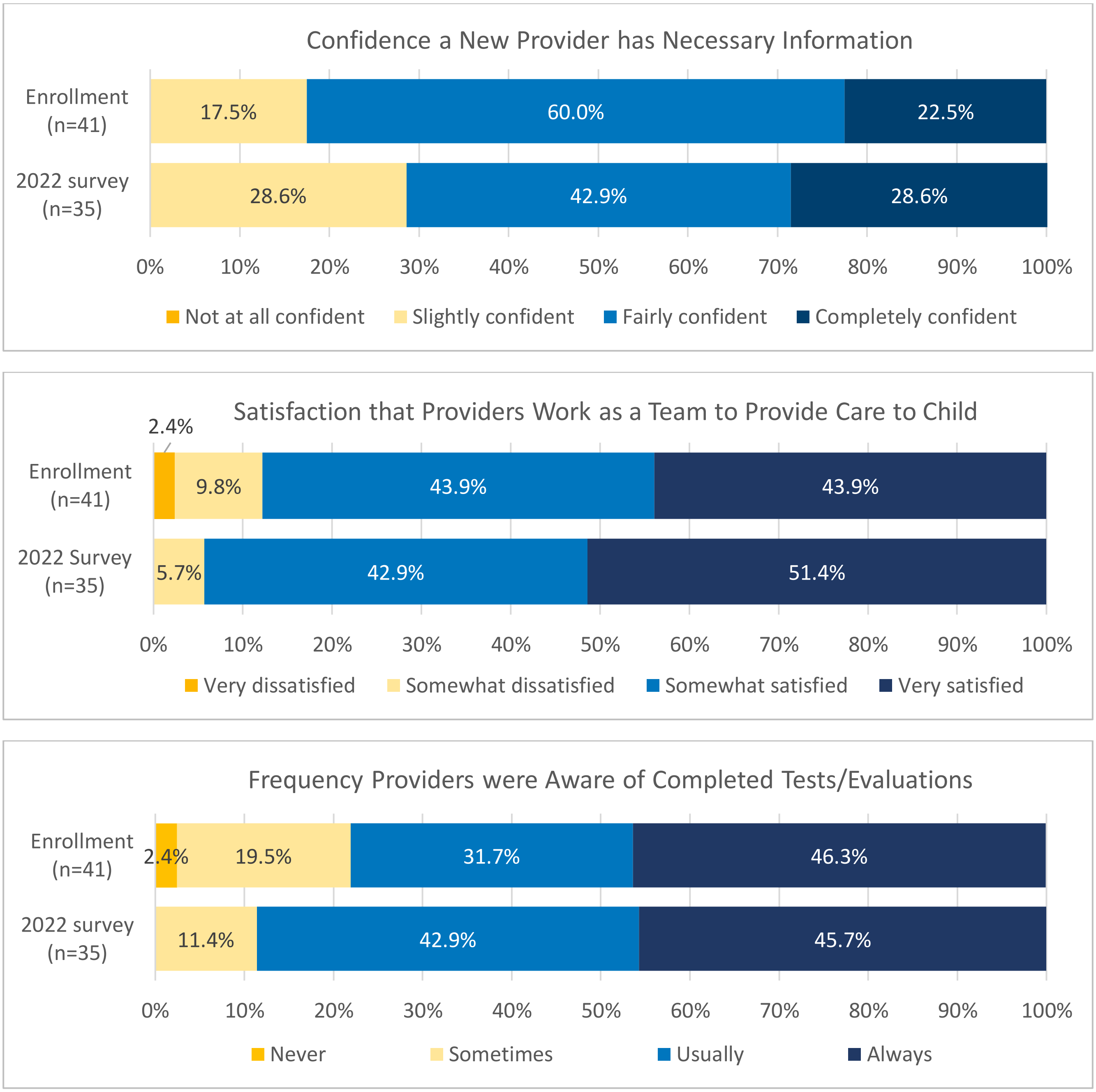
It is important to note that in 2022, well over half of the families surveyed still said that providers "never" or "rarely" asked caregivers how healthcare decisions for their children affected them personally.

Family Satisfaction

Did enrollment in the Sanford program result in greater family satisfaction overall? The answer is “yes” on the following three measures, illustrated in the charts below. The 2022 survey bar is at the bottom of each graph. The blue color shows higher levels of satisfaction.

Confidence that a new medical provider has all the information necessary to treat a child, satisfaction that medical providers work as a team to care for the child, and the frequency with which medical providers were aware of already completed tests all increased between enrollment and 2022.

Figure 4. Perceptions of Healthcare Provider Communication



Confidence a New Provider has Necessary Information

Satisfaction that Providers Work as a Team to Provide Care to Child

Frequency Providers were Aware of Completed Tests/Evaluations

Recommendations

1	Involve families in the further growth and development of the Sanford Patient Navigation Program, to ensure that it continues to meet their needs. This involvement might take the form of a parent board that meets at regular intervals with the Medically Complex Care Management team to discuss what is and is not working with the program.
2	Expand collaboration between providers, families, and community organizations. Parents often feel isolated as they face the challenges and the joys of raising children with medical complexity. A parent support group could allow these caregivers to offer nurturing and support to each other.
3	Maintain strong relationships with community organizations to encourage them to cohesively offer coordinated assistance to families. A yearly gathering of organizations from across the community, hosted by the Sanford program, could allow representatives to share the resources they are able to provide to families of children with medical complexity. Parents mentioned especially needing information on financial assistance and on transportation to and from medical appointments.
4	Offer training to ALL providers on how to talk to and care for parents. Parents of CMC have much to share with doctors, nurses, and others about their needs, needs that they indicate are largely unmet by the medical establishment. Make it a goal that each medical provider, at least once a day, says to a caregiver, "…and how are YOU doing?"
5	Urge all healthcare team members to become familiar with respite care services throughout the area served by the Sanford program. Make this information available to parents, and suggest they consider using these services regularly for their own well-being.
6	Collect qualitative interview data from parents to provide more detailed information on the needs of families and how they are or are not being met. Plans to do this are currently underway.

Program Participants

Two methods were used to gather patient and family demographic information. First, families were asked to provide household size and income on the 2022 survey. The average household size reported among the 35 responding families was 4.7 people, with an average of 2.4 children. Many (74.3%) had more than one child 18 years old and younger living at home. Eighteen of the 35 respondents provided household annual income, with a mean income of $57,014, ranging from $2,300 to $180,000 annually.

Aggregate information was also pulled from the patients' medical records. The mean age of the 41 participants was 3.4 years, with 78.1% of the participants under age 5, and 4.8% age 14 or older. Gender was 56.1% male, and racial distribution was 78% Caucasian and 22% American Indian. Patients resided in 17 counties in South Dakota, with about half living 100 miles or farther from Sioux Falls. Sixty-six percent of patients had Medicaid as their only insurance. The remaining 14 patients had Medicaid as their secondary insurance, with a private company as the primary provider.

Across the 41 participants, the mean number of medical diagnoses, defined as separate ICD-10 diagnostic codes (codes used by health systems to identify conditions/diseases, health problems, symptoms, testing results, or injuries) in the medical record, the year prior to enrollment in the program, was 26.4, with 58.5% having 20 or more diagnoses. The mean number of diagnoses dropped in the first year of enrollment in the program to 18.6 diagnoses with 39.0% of patients having 20 or more diagnoses.

Healthcare utilization data also were pulled from the patient's medical records and aggregated (Table 1). Only 19 of the 41 patients had been in the program for a full two years, limiting data availability. Data were compared between the year prior to enrollment, first year in the program (Year 1) and second year in the program (Year 2), where available. The number of medical visit days was significantly lower in Year 1 at a mean of 42.3 days compared to a mean of 59.3 days prior to participation in the program ($p<0.01$). The mean number of health providers and all providers increased significantly from the year prior to participation in the program compared to the first year of participation ($p<0.01$).

Cancel and no-show appointments were significantly higher in the first year of participation at a mean of 28.3 visits cancelled/no-show visits compared to just 9.7 visits the year prior to enrollment. Roughly half of this group enrolled in 2020, during the peak of the COVID-19 pandemic, which likely increased to some extent cancel and no-show appointment rates. The portion of participants with a past-year hospital stay declined from 73.2% to 65.9% but was not statistically significant ($p = 0.170$). Emergency department (ED) visits were stable, with about half of participants reporting one or more ED visits in the year prior to enrollment and during the first year in the program.

Table 1. Past Year Healthcare Utilization Metrics

	Medical Visit Days	Medical Providers	All Providers	Cancel/ No-Show Visits	Hospital Stays	ED Visits
Year Prior to Enrollment (n=41)	59.3 days (range: 10 to 170 days)	7.9 providers (range: 3 to 19)	15.3 providers (range: 4 to 40)	9.7 visits (range: 0 to 64)	73.2% had 1+ hospital stay	51.2% had 1+ ED visit
Year 1 (n=41)	42.3 days (range: 3 to 134 days)	14.9 providers (range: 5 to 38)	21.3 providers (range: 5 to 51)	28.3 visits (range: 0 to 156)	65.9% had 1+ hospital stay	48.8% had 1+ ED visit
Year 2 (n=19)	26.1 days (range: 1 to 85 days)	15.5 providers (range: 4 to 38)	19.8 providers (range: 5 to 45)	21.9 visits (range: 1 to 88)	42.1% had 1+ hospital stay	36.8% had 1+ ED visit

Survey Findings: Experiences with Healthcare

Families were asked a variety of questions about their experiences with healthcare services in the past year. Many of the questions were taken from national surveys to allow for data comparability. Additional questions on communication, use of the shared plan of care, and family needs were added to better inform the Sanford Pediatric Complex Care Program of service use.

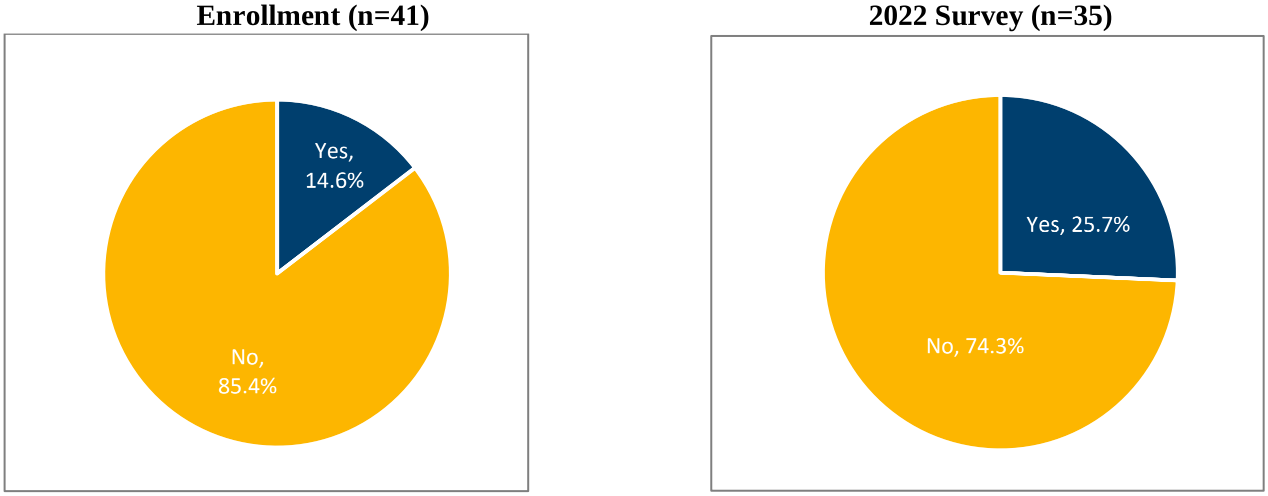
Medical Home Status

Evidence shows that caring for children in medical homes leads to improved health outcomes, decreased costs, and higher satisfaction levels.[2] The survey assessed the extent to which each participating family reported care in a medical home using the questions and analysis methods established in the National Survey of Children's Health (NSCH). Medical home status was assessed using the five recommended components that include: at least one consistent healthcare provider, a usual place for medical care, ability to easily receive referrals when needed, receipt of family-centered care, and effective care coordination.[3] When all five components are met, the child is classified as receiving care in a medical home.

The NSCH provides state and national comparison data for children with and without special healthcare needs, as well as a group identified as CSHCN, which is children with more complex care needs. CSHCN with more complex care needs are defined in the NSCH as children with one or more functional limitations, and/or above routine use of medical care, and/or requiring one or more prescription medications[3]--a group broader and less complex than patients enrolled in the Sanford Pediatric Complex Care Program. This should be noted when comparing the national and the local findings.

Among the 41 participating families, six (14.6%) identified as having coordinated, ongoing, comprehensive care within a medical home (Figure 5) at enrollment. This is much lower than national data showing that among CSHCN with more complex care needs, 37.8% nationally receive care in a medical home, and in the SD-only population 52.3% receive care in a medical home.[4] The 2022 survey showed a substantial improvement on this measure (Figure 1) with 9 families (25.7%) responding as receiving coordinated, ongoing, comprehensive care in a medical home.

Figure 5. Families Meeting Criteria for Receipt of Care in a Medical Home


Enrollment (n=41)

2022 Survey (n=35)

Access to Healthcare Services

Thirty-seven families (90.0%) of the 41 families reported having at least one personal healthcare provider in the 2022 survey. This is greater than the national rate among CSHCN with more complex health needs at 79.5% and the South Dakota-only rates at 86.7%.[4] Additionally, 73.2% of families in the Sanford program had a usual source for health care during the 2022 survey, lower than the national rate of 82.1% for CSHCN with more complex health care needs and the state rate of 90.8% for South Dakota-only children with special health care needs.[4] This rate was higher at the enrollment timepoint with 80.5% of families noting a usual source for healthcare.

Problems getting a referral when needed means the inability to see a doctor or receive medical services when required. Among the 41 participants in the 2022 survey, 17 (41.5%) families reported no problems getting referrals when needed. Seven (17.1%) families reported they had slight problems getting referrals when need. Eleven (26.8%) families reported that they did not need referrals during the past 12 months. At enrollment, 22 (80%) of the 41 families reported no problems getting referrals when needed. Seven additional families (17.1%) reported they had slight problems getting referrals when need, while not many had major problems getting referrals (2.4%).

Families were asked how confident they were that they could find care for their child when needed, rated on a scale from 1 to 10, where 10 was extremely confident, and 1 was not at all confident (Figure 6). Responses at enrollment ranged from 1 to 10, with a mean of 7.4 (SD 2.3). During the 2022 survey, the mean score increased to 8.4 (SD 1.6), with a range from 4 to 10, demonstrating a significant improvement in confidence in finding needed care ($p<0.05$).

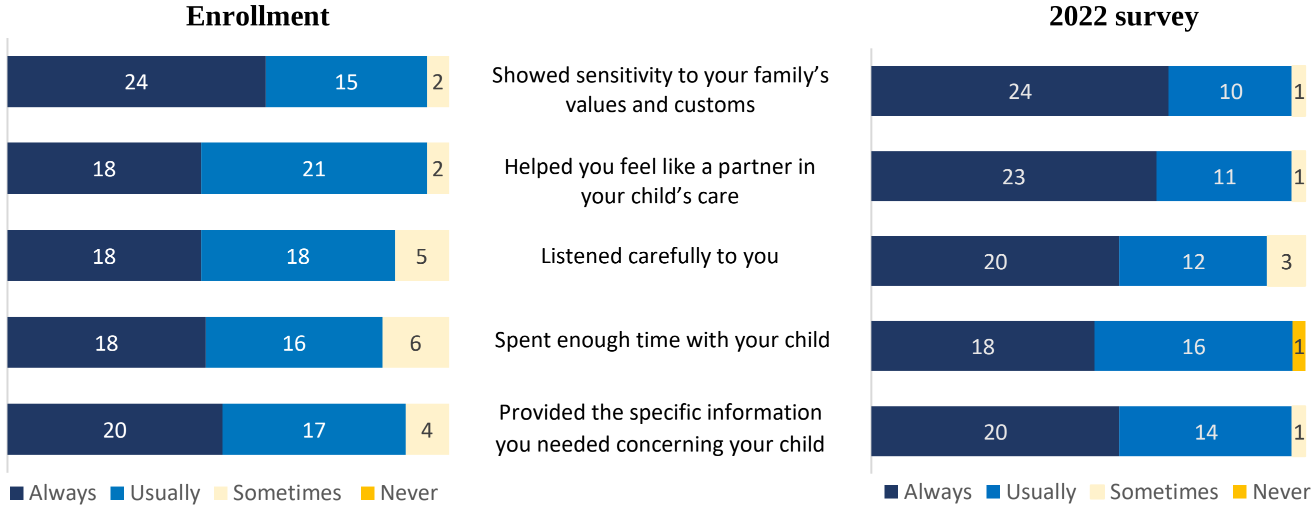
Figure 6. Confidence in Finding Needed Care for Child

Families were also asked to what extent their questions about their children's healthcare were addressed between scheduled appointments. Sixteen (45.7%) families reported they were addressed completely, and 16 (45.7%) families reported they were mostly addressed. Three families (8.6%) reported they were somewhat addressed.

Family Centered Care

The family centered care component of the NSCH is comprised of five questions including the extent to which the healthcare team spent enough time with the child, listened carefully, showed sensitivity to family values/customs, provided information specific to parents' concerns, and helped parents feel like partners in care. Across the 41 families, 75.6% reported receiving family centered care during the 2022 survey, lower than the national rate of 79.6% for the CSHCN with more complex health needs and the South Dakota-only rate of 84.0%.[4] This was an improvement over the enrollment survey, during which only 68.3% of the respondents reported receiving family centered care. Figure 7 shows that from the time of the enrollment survey to the time of the 2022 survey, the families perceived that the healthcare team more frequently provided specific information, spent more time with their children, listened to them more, helped them feel more like partners, and showed more sensitivity to their values/customs.

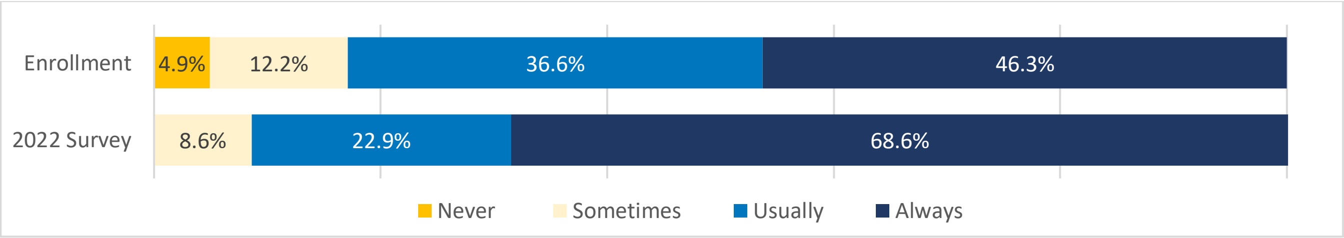
Figure 7. Families' Reported Frequency of Experiences with Healthcare Team



Shared Decision-Making with the Healthcare Team

Shared decision-making is a hallmark of family centered care. Three questions examined the extent to which the healthcare team provided information necessary for collaborative care. At enrollment, 92.6% of families indicated that information was usually or always provided by the healthcare team in a way that was easy to understand. This rate increased at the 2022 survey timepoint. Most participants (97.2%) indicated that information was usually or always provided by the healthcare team in a way that was easy to understand. Figure 8 shows that the portion of families reporting that the healthcare team always encouraged shared decision-making rose from 46.3% to 68.6% from enrollment to 2022 survey.

Figure 8. Extent to which the Healthcare Team Encouraged Family to Share in Decision-Making



Use of the Shared Plan of Care

A series of questions asked families to rate the frequency of which they were aware, contributed to, or communicated about a shared plan of care for their child. A shared plan of care, sometimes called a care plan, is a written document that contains information about a child's active health problems, medications, special considerations, and goals. A significant aim of the program is to promote the use of the shared plan of care for both routine and emergency care. When asked at enrollment, just ten families (24.4%) indicated that their child had a shared plan of care, eighteen (43.9%) indicated that they did not know, and thirteen (31.7%) indicated that their child did not have a shared plan of care. At the 2022 survey, 24 (68.6%) families were aware of the shared plan of care.

Level of satisfaction with the shared plan of care was assessed among those 24 families. Fifteen families (62.5%) indicated they were very satisfied with the plan, and seven (29.2%) indicated they were somewhat satisfied. Seventeen (70.8%) reported the child's care plan was shared with all of their child's healthcare providers and specialists, and twenty-two (91.7%) indicated they had received a paper or electronic copy. Seventeen (70.8%) noted the plan was updated or reviewed regularly.

Effective Care Coordination

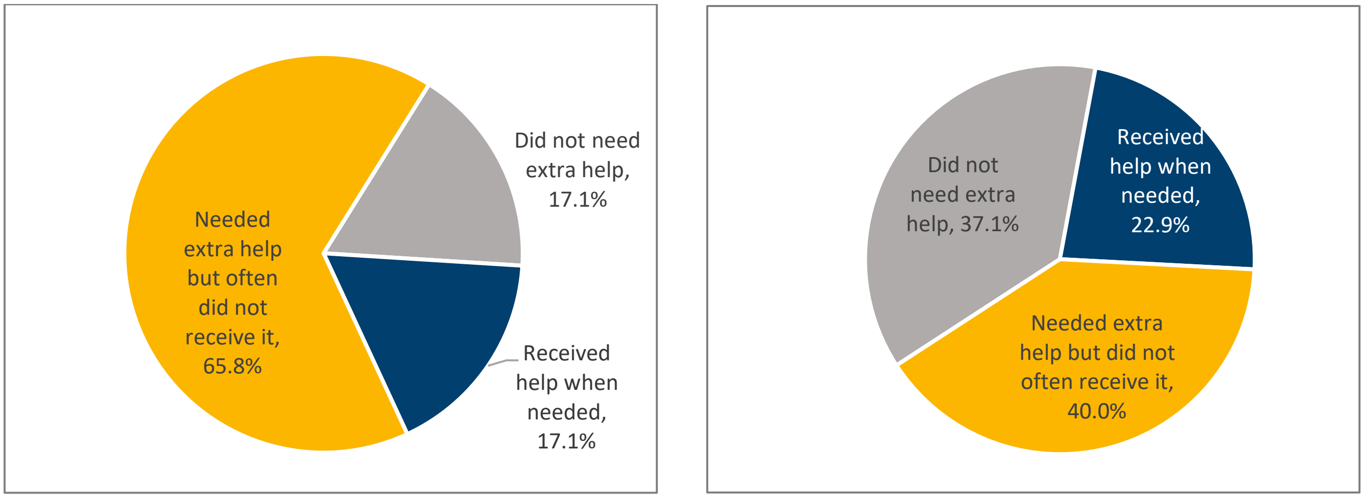
The final component of the medical home, effective care coordination, is comprised of three key factors – extent to which extra help in coordination is provided to the family, satisfaction with communication among healthcare providers, and satisfaction with communication to school, childcare, or special education programs. At enrollment, just seven of the 41 participating families or 17.1% reported receiving all needed components of care coordination, compared to 54.3% of CSHCN with more complex health needs nationally (with the SD sample size too small to report as valid).[6] By the 2022 survey, 34.3% of the 35 survey respondents reported receiving all needed components of care coordination, an increase of 17.2%.

Types of Care Coordination Needs

This component asks families to report if extra help is needed coordinating the child's medical appointments and healthcare needs. At enrollment, over half of participating families (65.8%) indicated they needed extra help with care coordination but did not receive it (Figure 9). By the 2022 survey timepoint, 40.0% of families indicated they needed extra help with care coordination but did not receive it, with 37.1% reporting they received the needed assistance.

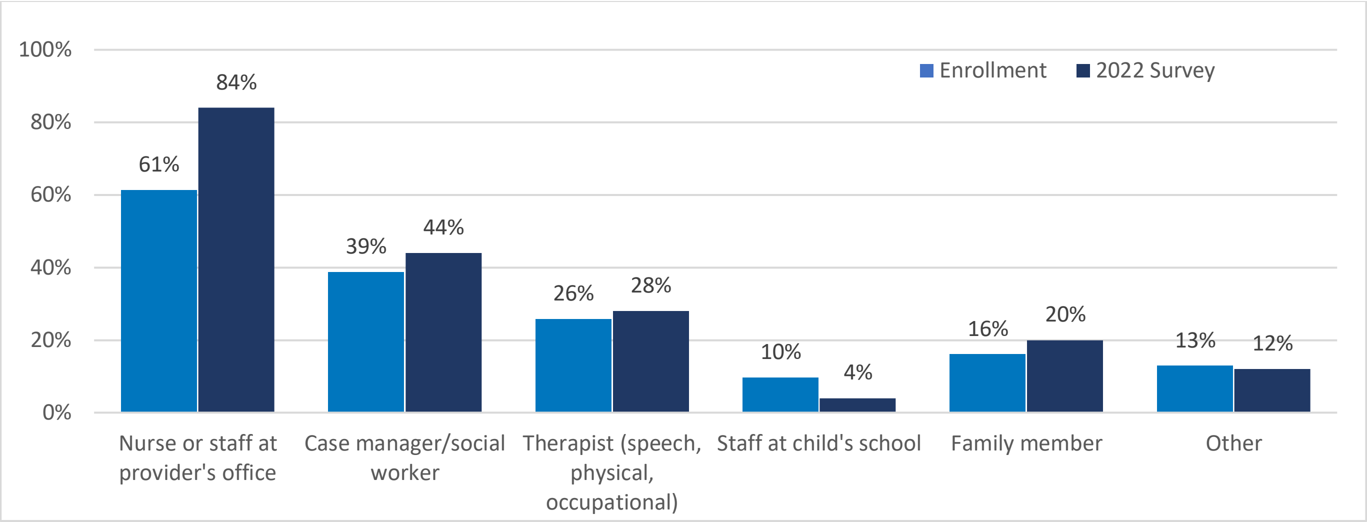
Figure 9. Care Coordination Needs

Enrollment (n=41) **2022 Survey (n=35)**



Families who noted that they received help with care coordination were asked to select the types of professionals providing this support (Figure 10). In the 2022 survey, 84.0% of responding families indicated that the nurse or staff at the healthcare provider's office had assisted the family with care coordination needs. Families were also less likely to select most other types of professionals as providing care coordination services during the 2022 survey. This may suggest that the program is addressing more of the family's needs, reducing the reliance on other professionals to provide these services.

Figure 10. Type of Professionals Providing Care Coordination in the Enrollment and 2022 Surveys



**Not summative, as respondent could select more than one.*

Respondents indicated the frequency they received specific medical coordination services as shown in Figure 11. The 2022 survey responses show that participants were more likely to report receiving all of the medical coordination services listed. The most frequently received services on the 2022 survey were a staff person to contact for support between provider visits and a staff person to help manage care transitions from location to location, clinic to clinic, or provider to provider. Providing same day appointments and scheduling longer appointments if need were among the least frequently received medical coordination responses on the enrollment survey but showed an important uptick by 2022.

Figure 11. Existing Medical Coordination Services

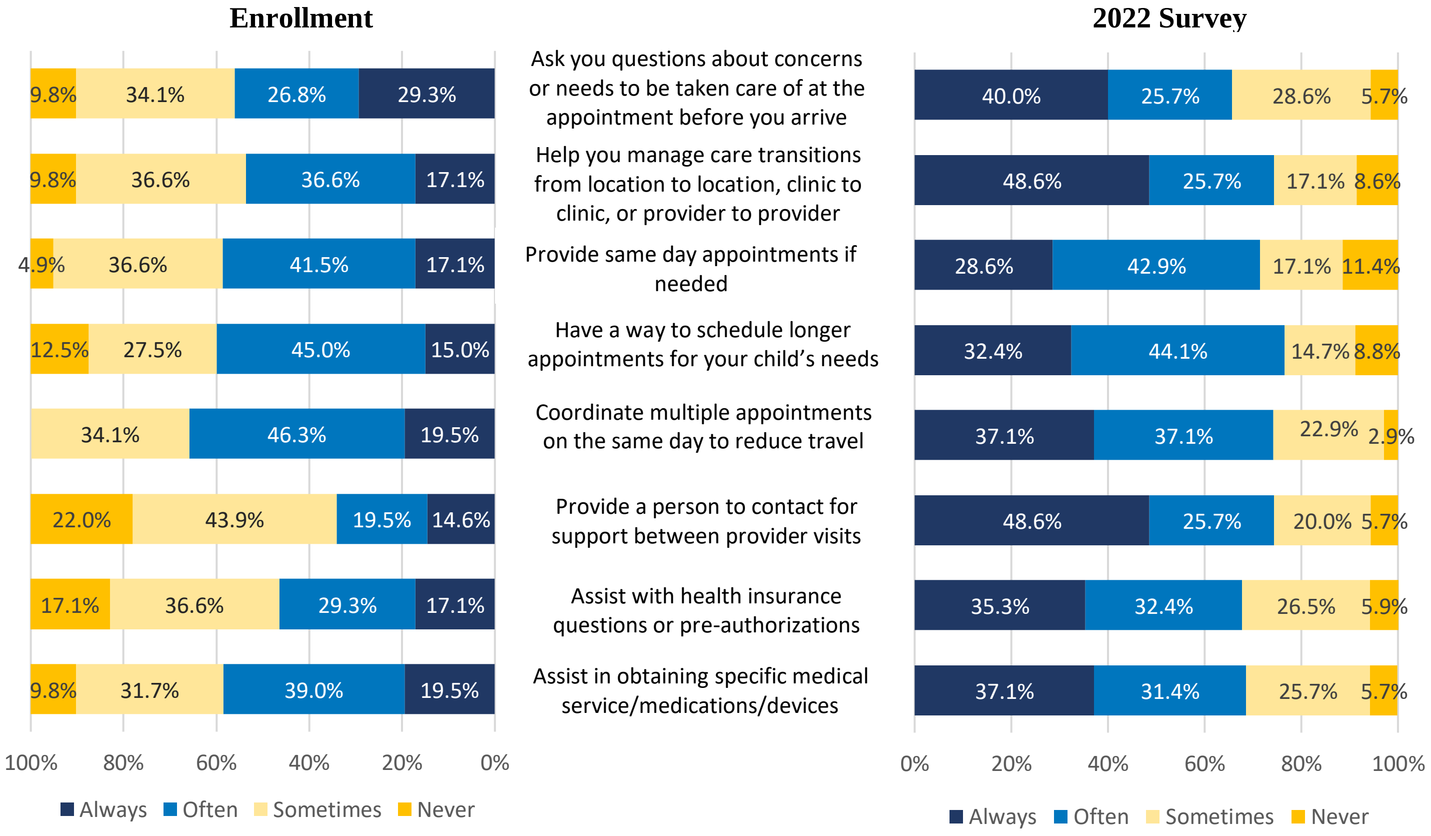
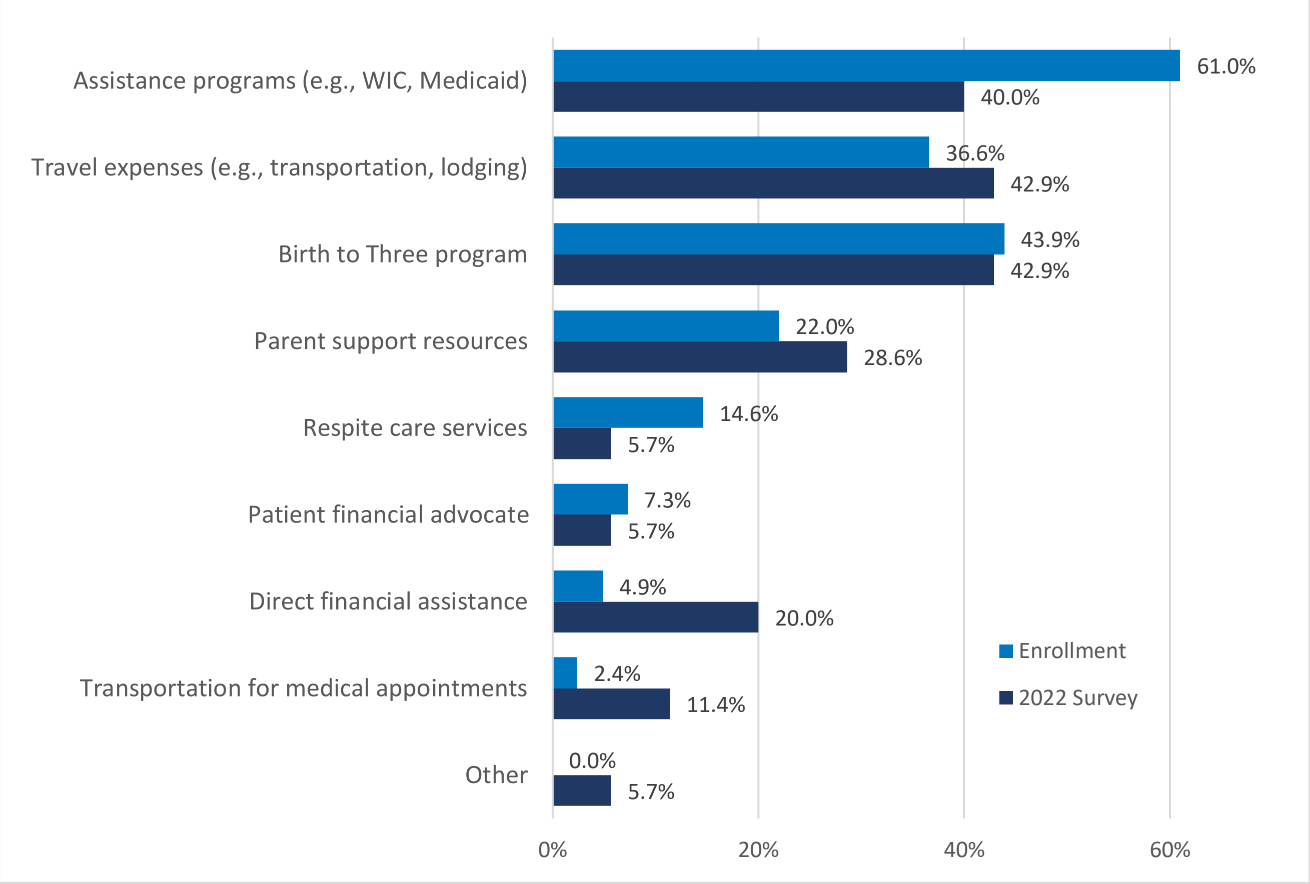


Figure 12 shows the reported community support coordination services provided at enrollment and at the 2022 survey timepoint. Support for travel expenses related to healthcare and transportation to medical appointments were more commonly received at the 2022 survey timepoint, while referral to assistance programs and the respite program were more commonly reported at the enrollment timepoint. One participant indicated receiving financial support for transportation. Another said some services were suggested, but finding providers was difficult.

Figure 12. Existing Community Support Care Coordination Services in the Enrollment and 2022 Surveys



**Not summative, as respondent could select more than one.*

Satisfaction with Communication across the Healthcare Team

At enrollment, 43.9% of the participating families were very satisfied with communication among healthcare providers, with the other half (51.2%) reporting being somewhat satisfied. This rate is lower than the national rate of 58.8% reporting very satisfied (with the SD sample size being too small to report as valid).[4] During the 2022 survey, 51.4% reported being very satisfied with communication among healthcare providers, 28.6% being somewhat satisfied, and 20.0% being somewhat dissatisfied or very dissatisfied.

Additional questions assessed family perceptions of communication between healthcare team members, as outlined in Figure 10. Confidence that new providers had necessary medical information about the child improved, with 28.6% of families indicating they were completely confident at the 2022 survey timepoint compared to 22.5% at the enrollment timepoint. An improvement was also found in the level of satisfaction with providers working together to provide care, with 51.4% of families selecting very satisfied during the 2022 survey. Improvements from enrollment to the 2022 survey were also noted on the question about providers awareness of medical tests being completed, with 45.7% of families selecting the provider was always aware of tests having been completed at the 2022 survey timepoint.

Satisfaction with Communication with Educational Entities

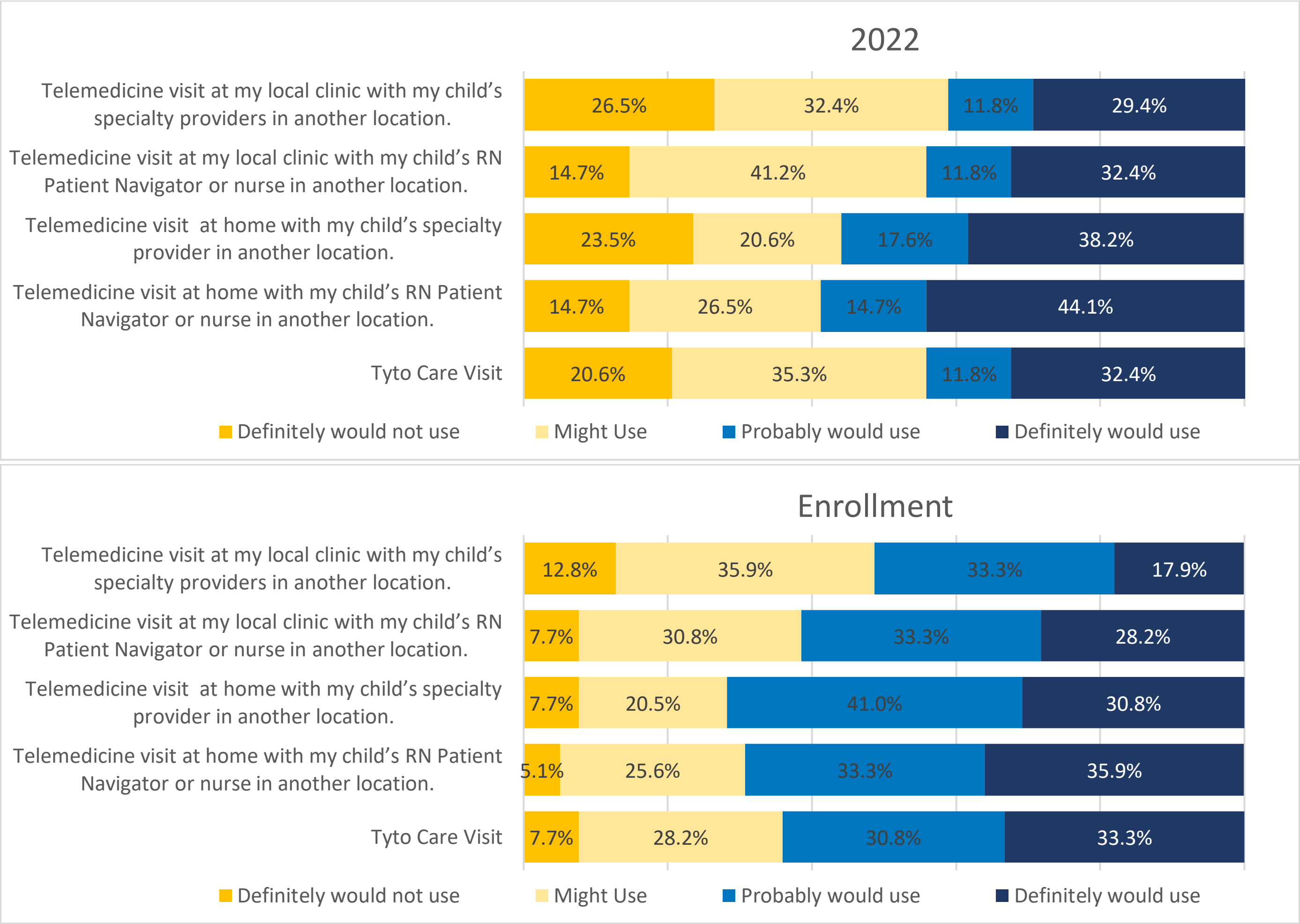
Sixteen participants in the 2022 survey reported that their children attended neither school nor childcare. Of the remaining 19 survey respondents, fourteen reported that their children attended school only, three participants reported that their children attended childcare only, and two participants reported that their children attended both school and childcare.

Satisfaction with communication between the educational entity and healthcare providers was assessed. Among the nineteen families with a child in school and/or childcare, only five families reported a need for communication between providers and the educational system. Fourteen reported that no communication was needed or that they did not have a healthcare visit to report during the past 12 months. Two of the five families (40%) reported that they were very satisfied with the communication among their child's school, childcare provider, or special education program, with the remaining 60% reporting lower levels of satisfaction.

Telemedicine Use

Telemedicine can help families who have difficulty accessing healthcare by other means. On the 2022 survey, 15 of the 34 responding families (44.1%) reported a telemedicine visit in the past 12 months (one family did not respond). Thirteen of the 15 families who received telemedicine care had a visit from their home with a healthcare provider while two had a telemedicine visit from their local clinic to a provider in another location. Interest in telemedicine remains varied, with more families indicating responses on either ends of the scale in 2022 (Figure 13).

Figure 13. Interest in Telemedicine



Survey Findings: Family Needs

Parental Distress

Parents of CMC (as well as other family members) provide immense levels of medical care to their children. The physical, social, psychological, and financial toll of this often leads to significant distress.[5-7] Families were asked if the healthcare team inquired about how the child's condition affected the family. At enrollment, only 10 of 41 respondents (24.4%) indicated that a member of the healthcare team had asked about family impact. This improved by the 2022 survey timepoint to 11 of 34 respondents (32.4%) indicating the same, with 18 families selecting 'no' and five families selecting 'I don't know.' Respondents were also asked to rate their current level of distress in the past week on a scale from 1 to 10, where 1 represented no distress and 10 represented extreme distress. As shown in Figures 14 and 15, responses were diffuse across both timepoints. At enrollment the mean distress rating was 5.1 (SD 2.8), and the mean rating was 4.4 (SD 2.4) on the 2022 survey, which was a statistically significant difference ($p<0.05$).

Figure 14. Distress Level of Parents

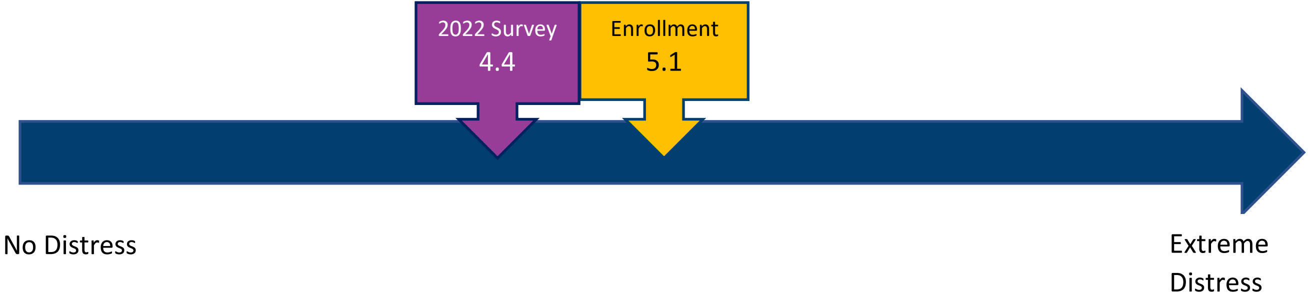
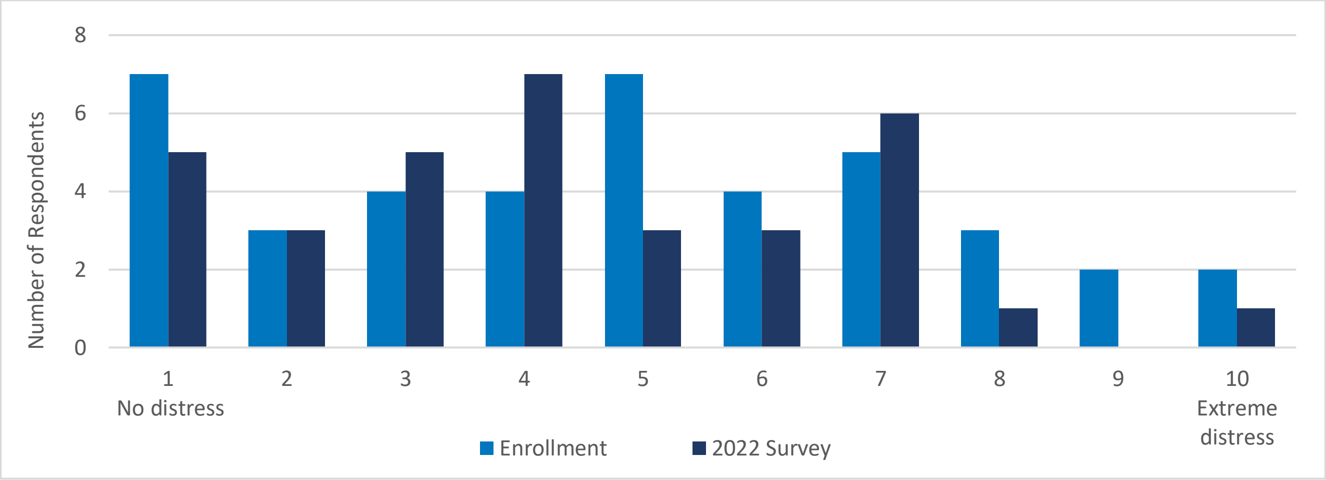


Figure 15. Frequency of Reported Level of Distress, Scale of 1 to 10



Challenges

Families were asked about challenges in the areas of medical care, financial responsibilities, and community resources. Four families indicated no challenges in any area at enrollment, and seven families indicated no challenges in any area during the 2022 survey. Needs were examined from enrollment to 2022, with fewer families identifying unmet needs across nearly all areas. Access to care for substance use disorders, transitions and access to adult services for children, and language/communication barriers were much less commonly identified as challenges compared to others at both enrollment and in 2022. Interestingly, some challenges were identified more at both enrollment and in 2022 – travel expenses related to needed medical services, job loss/employment concerns, distance from needed specialty care, and not being eligible for public programs due to income criteria. The most frequently identified challenges remaining at the 2022 survey timepoint were travel expenses related to needed medical services and distance from specialty care. Some participants also noted "difficulty scheduling appointments" and "access to mental health services."

Financial Impacts

All participating families were asked if they had had problems paying for their child's medical or other healthcare related bills in the past year, using a standard question from the NSCH. In the nationwide sample of CSHCN with more complex health needs, 19.9% of families reported struggling to pay medical bills (with the SD sample size too small to report as valid).[6] Three of the Sanford Patient Navigation Program's goals relate to reducing the financial burden for families with CMC, including reducing the cost of unnecessary or redundant travel, assistance with financial resources, and navigating medical systems to enhance efficiencies. At enrollment, eight (19.5%) families acknowledged struggling to pay medical bills using the NSCH standard question. At the 2022 survey timepoint, six (17.6%) families acknowledged struggling to pay medical bills, responding to the NSCH standard question.

Participant Comments

Open-ended questions asked families to note anything that could be done to improve their experiences or their children's experiences with the healthcare team. Caregivers were asked to provide these additional comments to help the evaluation team better understand family experiences. Tables 2 and 3 display all participant comments.

Table 2. Participant Comments on Improving Experiences with Healthcare Team

What could be done to make your experience and your child's experience with the healthcare team better?	• *Can't think of anything.* • *Clear expectations and communication. Better coordination of appointments to reduce travel/missed work and school.* • *Coordinating more appointments on the same day since we are out of town.* • *Current team, no. About any future doctors, there is nothing that irritates a mother more with a complex care child than the doctor not taking time to review the medical history first before a visit.* • *Everything is great.* • *Find a way to see if a follow-up appointment is required, and if so, when is that? 3 months, 6 months, etc. Right now, there is no way to see if I missed a follow-up for my son when the doctor wanted one.* • *I am more than happy with the efforts of the care team members. They're very supportive and attentive.* • *More understanding and more listening to us as parents.* • *No, I am pretty satisfied.* • *No, I love the team and care she gets.* • *No, I am satisfied with everything.* • *Not at this time.* • *Not that I can think of.* • *Not that I can think of. [Child name]'s team is amazing as is.* • *Right now, I am happy with [child name]'s care team and have no complaints. I am extremely upfront and direct and have no issues communicating. We have a great team currently, and we address any issues as they arise!* • *Since we live out of town, try to get appointments on the same day or next day.* • *Helping us make all the appointments.* • *We live five hours away from Sanford, so more communication about appointments closer to home would have been nice.*

Table 3. Participant Comments on the Sanford Children's Medically Complex Care Program

What would help us better understand your experiences with the Patient Navigation Program?	• *I am very happy that this hospital has a care team for patients with multiple doctors. It eases the stress on me and helps me organize appointments with people that care. I am grateful for their help!* • *No. Covered well.* • *No. This program has been a huge blessing to our family. We appreciate everything done for us.* • *There needs to be more information given about programs like Family Support 360. Information needs to be given to parents early on. They need help navigating that program.* • *We are still lucky enough to have Medicaid as secondary but once that goes away, it will be VERY stressful. Not sure how we will be able to afford our daughter's care.* • *We currently have Medicaid for our daughter, but we are concerned about when we no longer qualify.* • *We were really excited for the navigation program. There was a lot going on, and we were very overwhelmed. It started out strong, and then we got lost in the shuffle of coordination. Now that our daughter's health is getting better, we don't necessarily need this program as much as we did a year ago. I wish we had more support a year ago as we had to figure a lot of this out on our own. But we are so grateful for the help we have received.* • *Would love to see more support groups in the hospital while child is an inpatient.*

References

1. Kerkvliet, J. L., Wey, H., Jodozi-Molengraaf, C. (2018, June*). 2018 Children with Special Health Care Needs in South Dakota.* [Research Report]. Brookings, SD: South Dakota State University, Office of Nursing Research.
2. National Resource Center for Patient/Family-Centered Medical Home. (2020). *Why is Medical Home Important?* Retrieved from https://medicalhomeinfo.aap.org/overview/Pages/Evidence.aspx. 3.
3. Data Resource Center for Child and Adolescent Health. (n.d.) *2018 National Survey of Children's Health Codebook*. Retrieved from https://www.childhealthdata.org/learn-about-the-nsch/nsch-codebooks
4. Data Resource Center for Child and Adolescent Health. *2017-2018 National Survey of Children's Health (NSCH) Interactive Data Query*. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. Retrieved from https://www.childhealthdata.org/browse/survey
5. Cousino, M. & Hazen, R. (2013). Parenting stress among caregivers of children with chronic illness: a systematic review. Journal of Pediatrics Psychology, 38, 809–828. DOI: 10.1093/jpepsy/jst049
6. Peckham, A., Spalding, K., Watkins, J., Bruce-Barrett, C., Grasic, M. & Williams, A. P. (2014). Caring for caregivers of high-needs children. *Healthcare Quarterly*, 17, 30– 35. DOI: 10.12927/hcq.2014.24017
7. Edelstein, H., Schippke, J., Sheffe, S., Kingsnorth, S. (2017). Children with medical complexity: a scoping review of interventions to support caregiver stress. *Child: Care, Health and Development, 43*(3), 323-333. DOI: 10.1111/cch.12430.

For Study Staff Only

Participant ID: ___________________

Patient Navigation Program for Children with Complex Medical Conditions

2022Survey

This survey is designed to gather information about your family's health care experiences as you start working with the new Patient Navigation Program team. Your input is very important to us as you are the expert in what types of services and support your child and family needs. Information from this survey, and the one you complete one year from now, will help us plan for how to best serve children with complex medical conditions and their families in the future. Thank you for your time and input.

The evaluation of the Sanford Patient Navigation Program is funded through an interagency agreement from the SD Department of Health Office of Child and Family Services to the Population Health Evaluation Center at South Dakota State University. The Office of Child and Family Services provides services to improve the quality, accessibility and effective use of health care.

Your Experiences with Health Care Services

1. When thinking about your child's medical care in the past 12 months, has it been through:
   - ☐ Sanford Children's Specialty Clinic or Hospital only?
   - ☐ Sanford Children's Specialty Clinic or Hospital, and another Sanford facility only?
   - ☐ Both Sanford facilities and healthcare providers in other health systems

2. When thinking about your child's medical care in the past 12 months, has it been:
   - ☐ In-state only?
   - ☐ More in-state care with some out-of-state care?
   - ☐ More out-of-state care with some in-state care?

3. If you received care out-of-state, what type of care was provided?

   ____

   ____

4. **During the past 12 months**, how often did your child's health care team:

	Never	**Sometimes**	**Usually**	**Always**
Spend enough time with your child?	☐	☐	☐	☐
Listen carefully to you?	☐	☐	☐	☐
Show sensitivity to your family's values and customs?	☐	☐	☐	☐
Provide the specific information you needed concerning your child?	☐	☐	☐	☐
Help you feel like a partner in your child's care?	☐	☐	☐	☐
Explain information in a way that was easy to understand?	☐	☐	☐	☐
Encourage your family to share in decision making?	☐	☐	☐	☐

5. **During the past 12 months**, how satisfied are you with the communication among your child's doctors and other health care providers?
   - ☐ Very dissatisfied
   - ☐ Somewhat dissatisfied
   - ☐ Somewhat satisfied
   - ☐ Very satisfied

6. When your child has a new health care provider, how confident are you that person has received the information and support needed to continue your child's medical care?
   - ☐ Not at all confident
   - ☐ Slightly confident
   - ☐ Fairly confident
   - ☐ Completely confident

7. How satisfied are you that your child’s health care providers act as a team to provide care and support to your child?
    - ☐ Very dissatisfied
    - ☐ Somewhat dissatisfied
    - ☐ Somewhat satisfied
    - ☐ Very satisfied

8. **In the past 12 months**, how often did you feel that your child’s care team members were aware of all tests and evaluations your child has had recently to avoid unnecessary testing?
    - ☐ Never
    - ☐ Sometimes
    - ☐ Usually
    - ☐ Always

9. Do you have one or more persons you think of as your child’s personal doctor or nurse?
   A personal doctor or nurse is a health professional who knows this child well and is familiar with this child’s health history. This can be a general doctor, a pediatrician, a specialist doctor, a nurse practitioner, or a physician’s assistant.
    - ☐ No
    - ☐ Yes, one person
    - ☐ Yes, more than one person

10. Is there a place you or another caregiver USUALLY take your child when he or she is sick, or you need advice about his or her health?
    - ☐ No
    - ☐ Yes →Where does this child USUALLY go first? *Please mark one box.*
        - ☐ Doctor’s Office
        - ☐ Hospital Emergency Room
        - ☐ Hospital Outpatient Department
        - ☐ Clinic or Health Center
        - ☐ Retail Store Clinic or “Minute Clinic”
        - ☐ School (Nurse’s Office, Athletic Trainer’s Office)
        - ☐ Some other place

11. **During the past 12 months**, did your child need a referral to see any doctors or receive any services?
    - ☐ No
    - ☐ Yes → How difficult was it to get referrals?
        - ☐ Very difficult
        - ☐ Somewhat difficult
        - ☐ Not difficult

12. **In the past 12 months**, to what extent were your questions about your child's health addressed between scheduled appointments?

☐ Not at all
☐ Somewhat
☐ Mostly
☐ Completely

13. Is there anything that can be done to make you or your child's experience with the health care team better?

____

____

____

____

____

14. Has your child had a telemedicine visit with a health care provider in the past year? *A telemedicine visit is a visit with a health professional using videoconferencing equipment, such as a screen or a phone.*

☐ No
☐ Yes, a telemedicine visit from my local clinic to a provider in another location.
☐ Yes, a telemedicine visit from my home with a provider.

15. If a member of your child's healthcare team offered the following telemedicine options to support your child's care (at no additional cost), how likely do you think you would be to use these options?

	Definitely would not use	**Might use**	**Probably would use**	**Definitely would use**
Telemedicine visit at my local clinic with my child's specialty providers in another location	☐	☐	☐	☐
Telemedicine visit at my local clinic with my child's Sanford Patient Navigation team in another location	☐	☐	☐	☐
Telemedicine visit from my computer/ tablet/phone at home with my child's specialty provider in another location	☐	☐	☐	☐
Telemedicine visit from my computer/tablet/ phone at home with my child's Sanford Patient Navigation team in another location	☐	☐	☐	☐
Tyto © Care Visit. A package that includes an exam camera, specific medical monitoring devices, and an app for your phone that allows you to connect with your health care team from home.	☐	☐	☐	☐

Your Child’s Shared Plan of Care

A shared plan of care, sometimes called a care plan, is a written document that contains information about your child’s active health problems, medicines he or she is taking, special considerations that all people caring for your child should know, goals for your child’s health, growth and development, and steps to take to reach those goals. The following questions will ask about your child’s shared plan of care.

16. Does your child have a shared plan of care?
    - ☐ No *(Please skip to question 18.)*
    - ☐ I don’t know *(Please skip to question 18.)*
    - ☐ Yes→ How satisfied are you with your child’s shared plan of care?
        - ☐ Very dissatisfied
        - ☐ Somewhat dissatisfied
        - ☐ Somewhat satisfied
        - ☐ Very satisfied

17. Please indicate if the following statements about your child’s shared plan of care are true:

	No	**Yes**	**Don’t Know**
We (my child, myself, family members) had input into my child’s shared plan of care.	☐	☐	☐
My child’s care plan has been shared between all of my child’s health care providers and specialists.	☐	☐	☐
I received a paper or electronic copy of my child’s shared plan of care.	☐	☐	☐
My child’s health care team reviews and updates the shared plan of care with us (my child, myself, family members) regularly.	☐	☐	☐

Assistance with Managing Your Child’s Care

18. **During the past 12 months,** has anyone helped you arrange or coordinate your child’s care? *For example, coordinate care among the different providers or services that your child uses.*
    - ☐ No
    - ☐ Yes → Who provided help coordinating care? *[Check all that apply.]*
        - ☐ Family member or friend
        - ☐ Nurse or staff at my child’s health care provider’s office
        - ☐ Case manager/social worker
        - ☐ Therapist (speech, physical, occupational)
        - ☐ Someone at my child’s school
        - ☐ Other: ________________________________

19. **During the past 12 months**, have you felt that you could have used extra help arranging or coordinating your child’s care among the different health care providers and services?
    - ☐ No
    - ☐ Yes → How often did you get as much help as you wanted with arranging or coordinating your child’s care?
        - ☐ Never
        - ☐ Sometimes
        - ☐ Usually

20. How often does your child’s health care team:

	Never	Sometimes	Often	Always
Ask you questions about what concerns you have or what needs to be taken care of at the appointment before you arrive?	☐	☐	☐	☐
Help you manage care transitions from location to location, clinic to clinic, or provider to provider?	☐	☐	☐	☐
Provide same day appointments if needed?	☐	☐	☐	☐
Have a way to schedule longer appointments if your child needs one?	☐	☐	☐	☐
Coordinate multiple appointments on the same day to reduce travel costs and missed work/school?	☐	☐	☐	☐
Provide a person to contact for support between provider visits?	☐	☐	☐	☐
Assist with health insurance questions or pre-authorizations for insurance?	☐	☐	☐	☐
Assist in obtaining specific medical service/ medication/device?	☐	☐	☐	☐

21. **In the past 12 months**, in addition to providing medical care, which of the following community support services has your child’s health care team provided? *Check all that apply*.
    - ☐ Helped my family identify and apply for other assistance programs (e.g., WIC, food stamps, Medicaid, pharmacy assistance, childcare assistance)
    - ☐ Connected my family to the Birth to Three program
    - ☐ Assisted with travel expenses related to needed medical services (e.g., transportation, lodging, meals)
    - ☐ Referred my family to the patient financial advocate
    - ☐ Connected my family to direct financial assistance
    - ☐ Connected my family to respite care services
    - ☐ Provided information on parent support groups or resources
    - ☐ Transportation for medical appointments when needed
    - ☐ Other: ____

Your Experiences with Educational Services

22. **In the last 12 months**, did your child attend school or childcare?
    - ☐ No *(Please skip to question 24.)*
    - ☐ Yes, school only.
    - ☐ Yes, childcare only.
    - ☐ Yes, both school and childcare.

23. **During the past 12 months**, did your child's health care team communicate with your child's school, childcare provider or special education program?
    - ☐ No
    - ☐ My child did not need a health care provider to communicate with these providers.
    - ☐ Yes → Overall, how satisfied are you with the health care provider's communication with the school, childcare provider, or special education program?
        - ☐ Very dissatisfied
        - ☐ Somewhat dissatisfied
        - ☐ Somewhat satisfied
        - ☐ Very satisfied

Transition to Adult Care

The next set of questions ask about your experience and plans for the transition of your child's care into the adult health care setting. These questions target children age 14 and older only.

24. Please select the appropriate age category for your child.
    - ☐ My child is age 14 or older.
    - ☐ My child is under age 14. *(Please skip to question 27.)*

25. Has your child's healthcare team talked with you about <u>when</u> your child will need to see doctors or other health care providers who treat adults?

    ☐ No ☐ Yes ☐ I don't know.

26. Eligibility for health insurance often changes in your adulthood. Do you know how this child will be insured as he or she becomes an adult?
    - ☐ No → Has anyone discussed with you how to obtain or keep some type of health insurance coverage as your child becomes an adult?
        - ☐ No
        - ☐ Yes
    - ☐ Yes, my child will have insurance as he/she becomes an adult.

About You and Your Child

The next set of questions asks about the time you spend managing your child's health care and other services.

27. Have you or other family members stopped working because of your child's health?

☐ No
☐ Yes

28. Have you or other family members cut down on the hours you work because of your child's health?

☐ No
☐ Yes

29. **In the last 4 weeks**, about how many hours per week did you spend managing the care your child was getting from different doctors or care providers, including making sure that information was shared between all of these providers?

☐ Less than 1 hour each week
☐ 1 to 10 hours each week
☐ 11 to 20 hours each week
☐ 21 to 39 hours each week
☐ More than 40 hours each week

30. How stressful is it for you to manage your child's care?

☐ Very stressful
☐ Somewhat stressful
☐ A little stressful
☐ Not at all stressful

The next questions ask about your family and the support provided to your family related to your child's medical care.

31. How many people are living or staying at your current residence, including the child enrolled in the Patient Navigation Program?

Number of people: ____________________________

32. How many <u>children</u> are living or staying at your current residence, including the child enrolled in the Patient Navigation Program?

Number of children (age 18 and younger): ___________________________

33. What is the total income of everyone who lives in your house – the money you bring in plus the money other adults in the household bring in? *If you are unsure, your best guess is fine.*

Household income last year: _____________________________

☐ Don't know/prefer not to answer

34. I have been asked by my child's health care team how my child's condition affects our family (e.g., the impact on siblings, the time my child's care takes, lost sleep, extra expenses, etc.).

- ☐ No
- ☐ Yes
- ☐ I don't know

35. On a scale of 1 to 10, please circle the number that best describes how much distress you have been experiencing in the past week including today. *Please circle the number of your response.*

1 2 3 4 5 6 7 8 9 10

No distress

Extreme distress

36. In the past 12 months, how often have your child's care team members talked to you about….

	Never	**Rarely**	**Sometimes**	**Usually**	**Almost Always**	**Always**
…things in your life that cause you stress because of your child's health or care needs?	☐	☐	☐	☐	☐	☐
…things that make it hard for you to take care of your child's health?	☐	☐	☐	☐	☐	☐
…how health care decisions for your child will affect your whole family?	☐	☐	☐	☐	☐	☐

37. On a scale of 1 to 10, how confident are you that you can find the care your child needs when they need it? *Please circle the number of your response.*

1 2 3 4 5 6 7 8 9 10

Not at all confident

Extremely confident

38. Does your child or family experience challenges in any of the following areas? *Please check all that apply.*

Medical care for you, your child, or family members

- ☐ Access to medical specialists
- ☐ Access to routine medical and preventive care
- ☐ Access to behavioral health care
- ☐ Access to care for substance use disorders
- ☐ Distance from needed specialty care
- ☐ Transition and access to adult services for my child
- ☐ Access to a specific medical service/medication/device, specify: ____

Financial Concerns

- ☐ Inadequate insurance coverage
- ☐ Medical expenses not covered by health insurance
- ☐ Travel expenses related to needed medical services (e.g. transportation, lodging, meals)
- ☐ Job loss/employment concerns
- ☐ Not eligible for public programs due to income criteria

Community Resources/Other

- ☐ Inadequate childcare
- ☐ Education on my child's medical conditions
- ☐ Lack of respite care
- ☐ Access to parent support groups
- ☐ Language/communication barrier
- ☐ Access to food assistance programs (e.g., food pantry)
- ☐ Lack of recreation and/or social activities for my child
- ☐ Waiting lists for programs, specify: ________________________
- ☐ Access to community services and resources, specify: ____________________
- ☐ Other: _______________________________________

☐ **None of the above are challenges for my family.**

39. **In the past 12 months,** did your family have problems paying for any of your child's medical or health care bills?

- ☐ No
- ☐ Yes

40. Is there anything we did not ask about that would help us understand your experiences with your child's health care, support system, or services you use?

____

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____

____

Thank you for completing the survey!

Please place the survey in the addressed, postage-paid envelope and return it to the Sanford Patient Navigation Program team.

If you have any questions about the survey, please contact Jenny Kerkvliet at South Dakota State University, 605-688-4131 or Jennifer.Kerkvliet@sdstate.edu.