Supporting Children with Medical Complexity

Post-Program Outcomes and Perceptions of Families

March 2022

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POPULATION HEALTH EVALUATION CENTER

Sanford Patient Navigation Program for Children with Medical Complexity

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 program started with support from the SD Department of Health to address the needs of CMC identified both through pediatric specialty provider experiences' and a statewide survey[1] of families with children with special healthcare needs (CSHCN).

The Patient Navigation Program for CMC employs a Registered Nurse (RN) Patient Navigator who is the point of contact to improve communication among affiliated professionals and community support programs. In addition, this individual aids families in navigating the complex healthcare system with the goal of improving care. The first cohort of the program targeted rural CMC. The distribution of pediatric specialty services in SD presents a unique challenge because essential medical and support services are often a long distance from the child's home. The CMC program priorities include:

1) Coordination of complex care across the healthcare spectrum
2) Navigating medical systems to enhance efficiencies
3) Decrease 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 transitions of care
9) Assistance in financial resources and comprehension of aspects of care

Additional information on the program's history, structure, and eligibility criteria are available in a separate report, *Supporting Children with Medical Complexity: Pre-Program Perceptions of Families*, which can be obtained from the Sanford CMC Patient Navigation Program Director or the CYSHCN Director at the South Dakota Department of Health.

Program Evaluation and Methods

Evaluation of the Sanford Navigation Program for CMC examined health outcomes, family needs, provider perceptions, care coordination, cost considerations, and family stakeholder communication before and after program participation using three specific aims. The first aim was to assess the family's satisfaction with care coordination and planning, focusing on barriers to receiving adequate care and unmet family and medical needs. The second aim was to examine the perceptions of professionals affiliated with the participating families. The final aim was to gather information about the types of services provided by the RN Patient Navigator to refine and potentially expand future services. The project was reviewed by the Sanford Institutional Review Board with determination that the activities were not human subject research. This report outlines the procedures and results relative to the first aim, that is, family satisfaction with healthcare services, both before and one year after participation in the program.

Thirty families were recruited for the first cohort of the program by December 2020. Thirty families agreed to participate in the evaluation activities, to complete the enrollment survey and to share limited, de-identified medical information about their children. This information included age, gender, race, county of residence, and health insurance status, and medical service information (number of past year medical visit days, hospital stays, emergency department (ED) visits, county of primary care provider, number of unique diagnostic codes, and number of unique medical providers in the past year). Participant coding was managed by the Sanford RN Patient Navigator so that the identities of the participating families were unknown to the evaluation team. The Patient Navigator also invited participating families to complete the one-year post-survey.

Twenty-three of the thirty families completed the one-year post-survey, for a response rate of 76.7%. One family was removed from the evaluation project upon request. The remaining six families were coded as non-respondents to the survey but continued in the program. Medical information data was obtained for 27 patients in this cohort. Therefore, the number of participants for the healthcare metrics is 27 participants, and for the survey data is 23 participants.

Results

Participants

Two methods were used to gather patient and family demographic information. First, families were asked to provide household size and income on the survey. The average household size reported among the 30 participants at enrollment was 4.6 people, with an average of 2.3 children. Most (90.0%) had more than one adult in the household. Sixteen of the 30 respondents provided household annual income, with a mean income of $71,875.75, ranging from $10,512 to $180,000 annually.

Aggregate information was also pulled from the patients' medical records. The mean age of program participants at enrollment was 6.7 years. One-third (33%) of the participants were 2 years of age or younger, and another five participants (17%) were age 3 to 5. Seven participants (23%) were between ages 6 and 11, and eight (27%) between the ages of 12 and 17. Gender was 70% male, and racial distribution was 90% White and 10% American Indian. Patients resided in 14 counties in South Dakota, with 70% living 100 miles or farther from Sioux Falls. Sixteen 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 27 participants, the mean number of medical diagnoses in the past year, defined as separate ICD-10 or equivalent codes in the medical record, was not significantly different between the pre and post survey periods. There were 24.9 mean diagnoses at enrollment into the program (ranging from a low of 7 to a high of 63), and there were 22.9 mean diagnoses at post-survey (ranging from a low of 4 to a high of 50). Over 50 percent of the participants had 20 or more diagnoses in the past year at both timepoints.

Healthcare utilization data were also pulled from the patient's medical record and aggregated (Table 1). No statistically significant differences were identified across any of the assessed metrics from pre to post timepoints. The 27 patients had a mean of 44 days in the past year with one or more medical visits at enrollment, and a mean of 41 days with one or more medical visits at post-survey. The mean number of unique medical providers in the past year was 7.9 providers, ranging from 3 to 19 different providers, at enrollment, and 8.5 providers, ranging from 4 to 17 providers, at post-survey. Although not statistically significant (p=0.059), the number of no-show appointments overall dropped from a mean of 8.1 visits to a mean of 4.9 visits at the post-survey timepoint. Additionally, the total number of past year cancel or no-show visits across the 27 families at enrollment was 213, dropping to 133 cancel or no-show visits at post-survey, an important decrease.

The number of hospital stays varied, with 48.1% of patients having no hospitalizations in the past year at enrollment, another 18.5% with 1 hospital stay, and the remaining 33.4% with 2 to 10 hospital stays in the past year at enrollment to the program. Hospital stays were similar at the post-survey timepoint, with 44.4% having no hospitalizations, 22.2% having 1 hospital stay, and 33.4% having 2 to 7 hospital stays in the past year. Emergency department (ED) visits were uncommon, with 17 patients having no ED visits in the past year at enrollment, another 3 patients with one ED visit, and the remaining patients with 2 ED visits (n=2), 4 ED visits (n=4) and 8 ED visits (n=1). At the post-survey timepoint, 15 patients had no ED visits in the past year, 4 patients had one visit, 5 patients had three visits, and the remaining 3 patients had four, six, and nine visits to the ED in the past year.

Table 1. Past Year Mean Healthcare Utilization Metrics

	Medical Visit Days	Medical Providers	Cancel or No-Show Visits	Hospital Stays	ED Visits
Enrollment (n=27)	43.8 days (range: 10 to 141 days)	7.9 providers (range: 3 to 19)	8.1 visits (range: 0 to 27)	1.6 stays (range: 0 to 10)	1.2 visits (range: 0 to 8)
Post-survey (n=27)	40.6 days (range: 3 to 116 days)	8.5 providers (range: 4 to 17)	4.9 visits (range: 0 to 23)	1.4 stays (range: 0 to 7)	1.4 visits (range: 0 to 9)

Experience with Healthcare Services

Families were asked a variety of questions about their experiences and satisfaction with healthcare services at enrollment into the program, and again at the one-year post-survey timepoint. 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 inform the Sanford Patient Navigation Program services.

Medical Home Status

Methods for Determining Care in a Medical Home

The National Resource Center for Patient/Family-Centered Medical Home, a division of the American Academy of Pediatrics, advocates for medical homes for all children. Evidence shows that caring for children for in medical homes leads to improved health outcomes, decreased costs, and higher satisfaction levels.[2] A medical home is defined as a place where care is "accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective."[3] The pre-survey assessed the extent to which each participating family report care in medical home using the questions and analysis methods established in the National Survey of Children's Health (NSCH). The NSCH provides state and national comparison data for children with and without special healthcare needs, as well as a group identified as CSHCN 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 one or more prescription medications[4] - a group broader and less complex than CMC enrolled in the first cohort of the Sanford Patient Navigation Program. Medical home status was assessed using the five recommended components including having 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.[4] When all five components are met, the family is classified as receiving care in a medical home. The medical home is a national performance indicator for the Maternal Child Health Block grant.[5]

Medical Home Status Results

Among the 23 participating families, just three (13.0%) responded as receiving care in a medical home (Figure 1) 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.[6] The post-survey showed a substantial improvement on this measure (Figure 1) with 12 families (52.2%) responding as receiving care in a medical home.

Figure 1. Families Meeting Criteria for Receipt of Care in a Medical Home

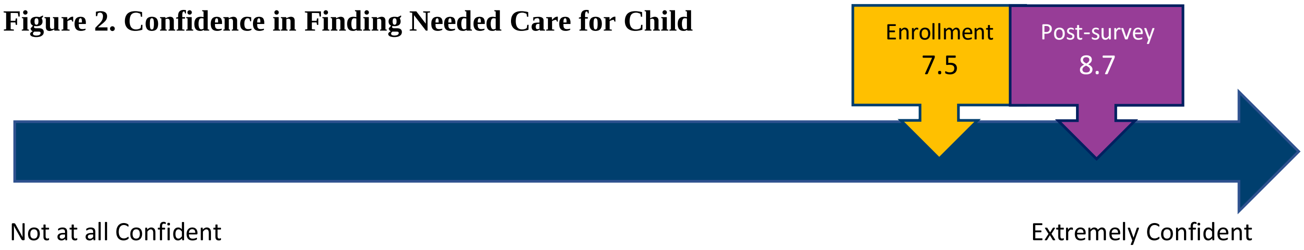
Access to Healthcare Services

All twenty-two of the twenty-three families reported having at least one personal healthcare provider at the one-year timepoint. This is much higher than the national rate among CSHCN with more complex health needs at 79.5% and SD-only rates at 86.7%.[6] Additionally, 87.0% of families in the program had a usual place for medical care at enrollment, similar to national rates at 82.1% of CSHCN with more complex health needs, and SD-only rates at 90.8%.[6] This rate was lower at the post-survey timepoint with 78.3% of families noting a usual place for sick care.

Problems getting a referral when needed is another factor in access to care. Among participants, two families (9.1%) reported it was very difficult to get referrals when needed at enrollment, much higher than the 2.5% of CSHCN with more complex health needs nationally (SD-only rate unavailable).[7] Two additional families (9.1%) reported it was somewhat difficult to get a referral, while many had no difficulty getting a referral (50.0%) or did not need a referral (31.8%). This metric showed improvement at the post-survey time point, with just three families noting a small problem getting a referral, and none indicating much difficulty with referrals.

Families were asked how confident they were that they could find the care their child needs when needed, on a scale from 1 to 10, where 10 was extremely confident and 1 was not at all confident (Figure 2). Responses at enrollment ranged from 4 to 10, with a mean of 7.5 (SD 2.1). At one-year, the mean score increased to 8.7 (SD 1.6), with a range from 6 to 10, demonstrating a significant improvement in confidence in finding needed care ($p<0.01$).

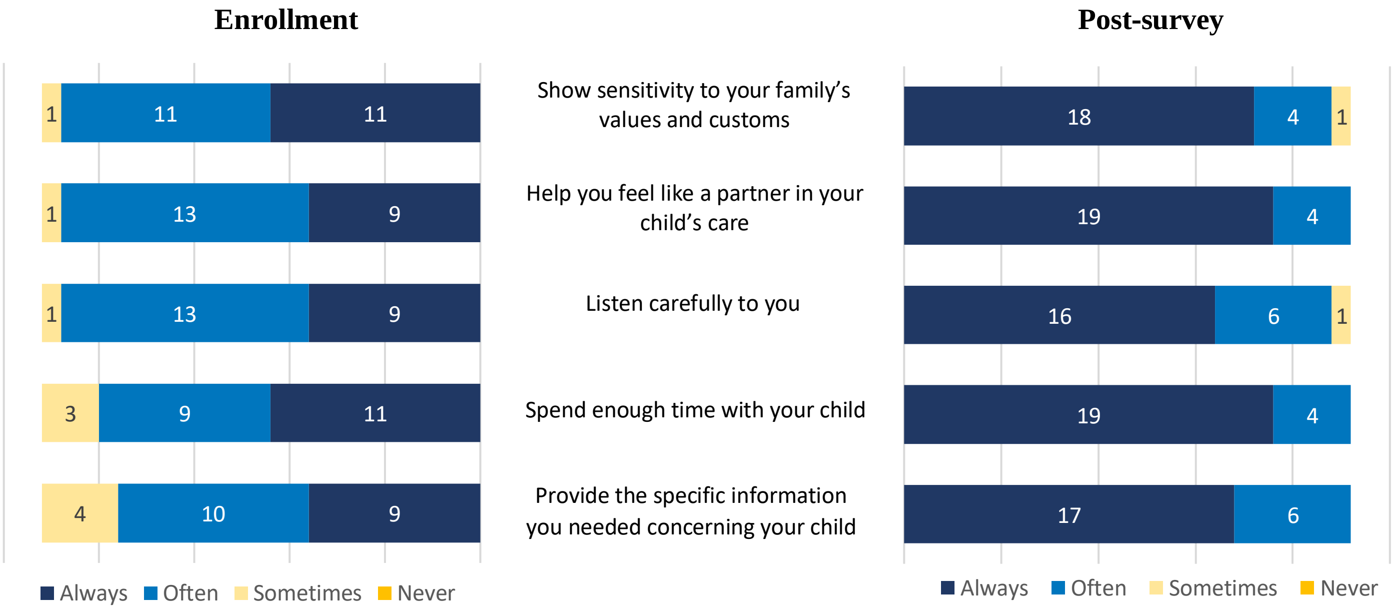
Figure 2. Confidence in Finding Needed Care for Child



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 twenty-two families, 69.6% reported receipt of family centered care at enrollment, lower than national rates at 79.6% of CSHCN with more complex health needs and 84.0% of SD-only respondents.[6] Substantial improvements were identified on this measure by the one-year survey, where 95.7% reported receiving family-centered care. Figure 3 shows that from enrollment to post-survey, the families perceived the healthcare team to more frequently provide specific information, spend time with the child, listen to the parent/guardian, help the family feel like a partner, and show sensitivity to family values than perceived at enrollment.

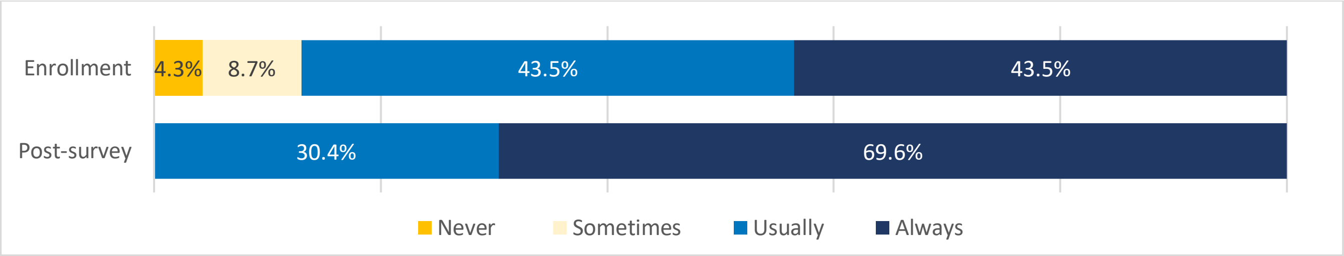
Figure 3. Families' Reported Frequency of Experiences with Healthcare Team



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. All participants at the one-year timepoints indicated that information was usually or always provided by the healthcare team in a way that was easy to understand. At enrollment, 82.6% of families indicated that their questions were mostly or completely addressed between scheduled appointments. This rate increased at the post-survey timepoint, with 91.3% indicating their questions were addressed between scheduled appointments. Figure 4 shows that the portion of families reporting that the healthcare team always encouraged shared decision-making rose from 43.5% to 69.6% from enrollment to post-survey.

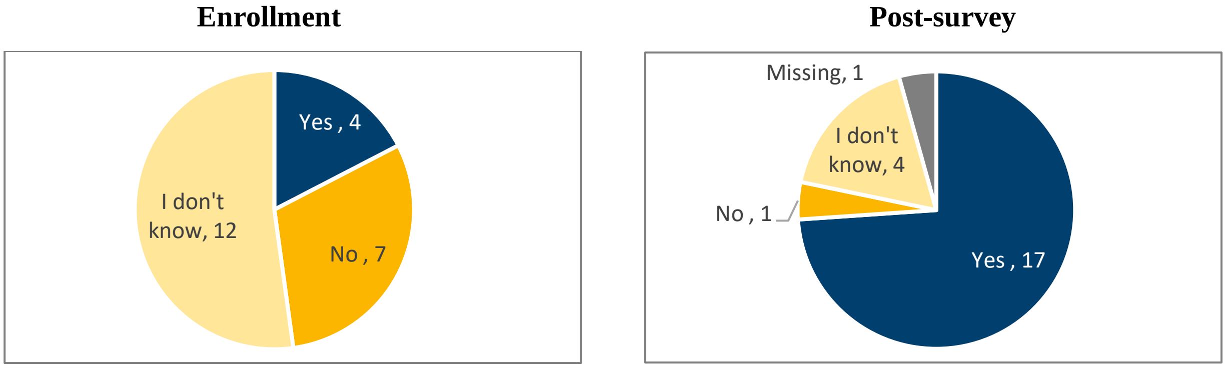
Figure 4. Extent to which the Healthcare Team Encouraged Family to Share in Decision-Making



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 goal 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 four families indicated that their child had a shared plan of care document, twelve did not know, and seven indicated their child did not have a shared plan of care (Figure 5). At the post-survey, 74% of families were aware of the shared plan of care.

Figure 5. Parental Awareness of Shared Plan of Care



Level of satisfaction with the shared plan of care was assessed at the one-year (post) timepoint among those who indicated their child has a shared plan of care. Twelve families (70.6%) indicated they were very satisfied with the plan, and the remaining five were somewhat satisfied. Sixteen of the seventeen families indicated that they had input into the plan, and all indicated they had received a paper or electronic copy. Most (88.2%) noted that the plan had been shared across the child's healthcare team (two were unsure) and fifteen also indicated that the plan was updated or reviewed regularly.

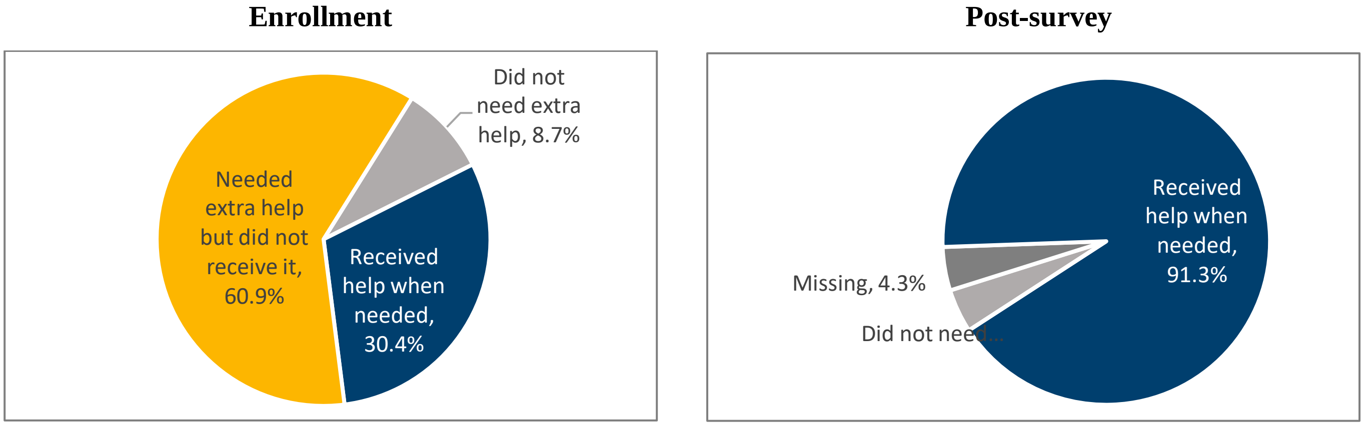
Effective Care Coordination

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 17.4% of the 23 participating families reported receiving effective care coordination, compared to 54.3% of CSHCN with more complex health needs nationally (with the SD sample size too small to report valid).[6] By the post-survey timepoint, 73.9% reported receiving effective care coordination, an increase of over 50%.

Types of Care Coordination Needs

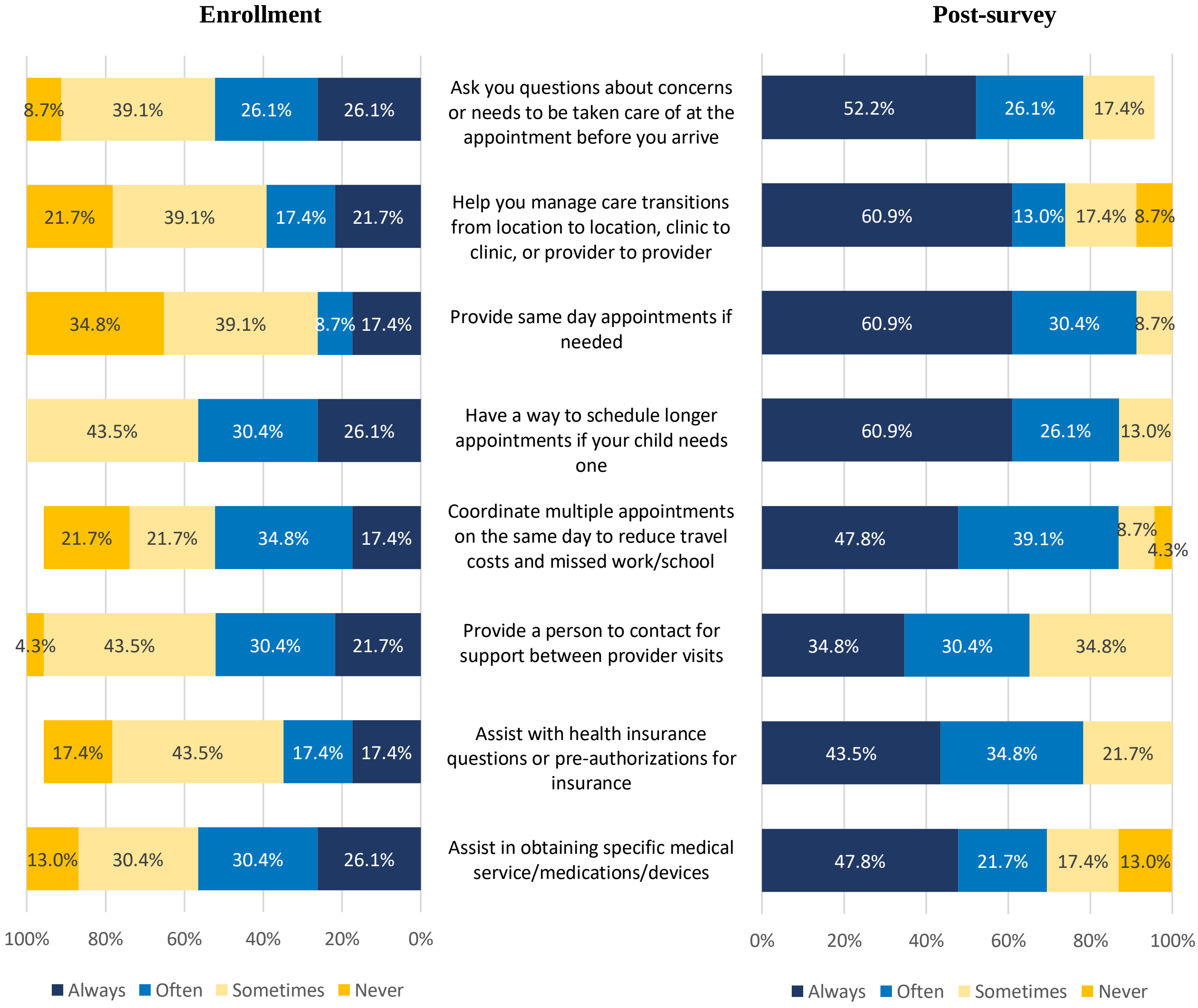
This component asks families to report if extra help is needed coordinating the child's medical appointments and healthcare needs. At enrollment, over half of participating families (61%) indicated they needed extra help with care coordination but did not receive it (Figure 6). By the post-survey timepoint, no families indicated unmet needs for care coordination, with 91% reporting they received the needed assistance.

Figure 6. Care Coordination Needs



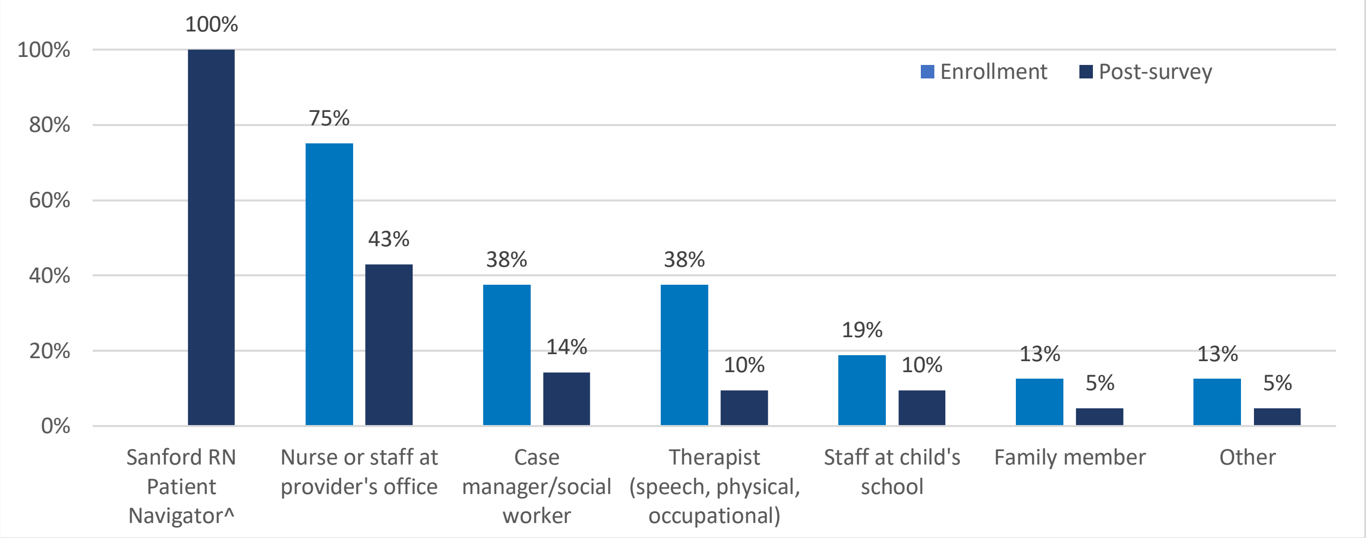
Respondents indicated the frequency of receipt of specific medical coordination services in Figure 7. Post survey responses show that participants were more likely to report receiving all of the medical coordination services listed. The most frequently received services reported on the post-survey were same day appointments, coordinating multiple appointments on the same day, and longer appointments if needed. Same day appointments and coordinating multiple appointments on the same day were among the least frequently received medical coordination services on the enrollment survey, showing important improvement.

Figure 7. Existing Medical Coordination Services



Families who noted that they received help with care coordination were asked to select the types of professionals providing this support (Figure 8). At the post-survey timepoint, 100% of responding families indicated that the Sanford RN Patient Navigator had assisted the family with care coordination needs. Families were also less likely to select all other types of professionals as providing care coordination services at the post-survey timepoint. This may suggest that the Patient Navigator is addressing the family's needs, reducing the reliance on other professionals to provide these services.

Figure 8. Type of Professional Providing Care Coordination in the Past Year, Post-survey*

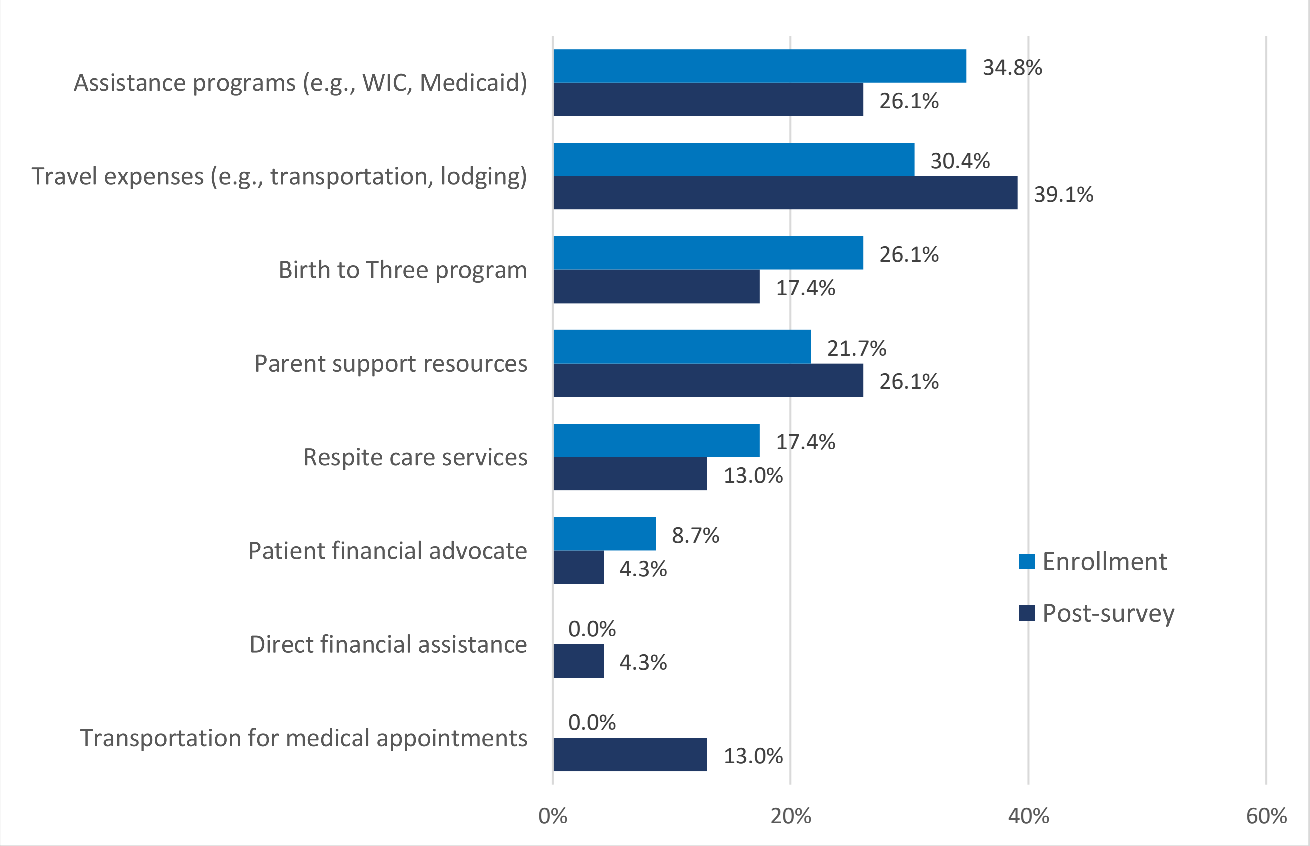


**Not summative, as respondent could select more than one.*

^ Sanford RN Patient Navigator was not an option on the enrollment survey, as the position had not yet started.

Figure 9 shows the reported community support coordination services provided at enrollment and at the one-year post-survey timepoint. Support for travel expenses related to medical care and transportation were more commonly received at the post-survey timepoint, and referral to assistance programs and the Birth to Three Program were more commonly reported as received at the enrollment timepoint.

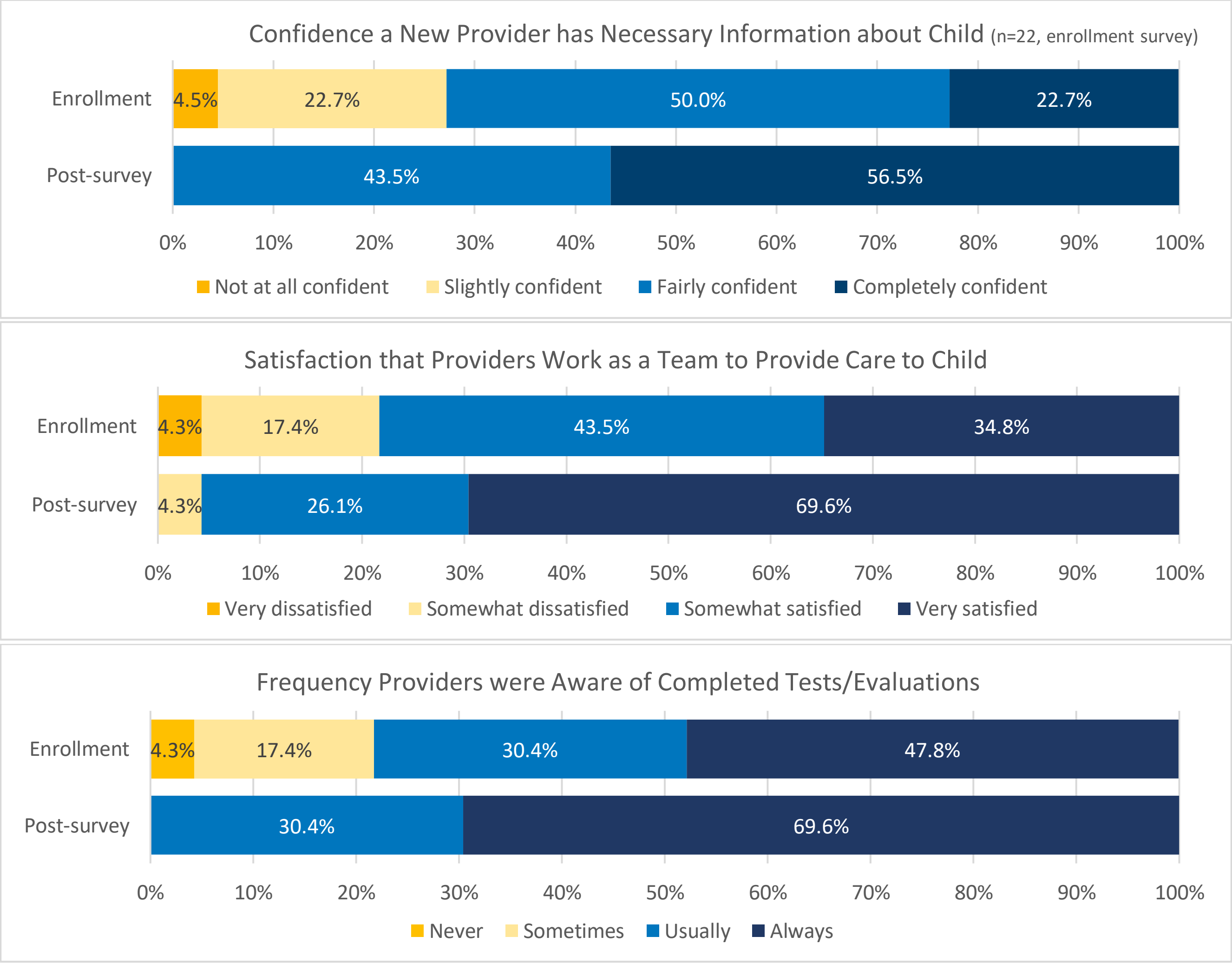
Figure 9. Existing Community Support Care Coordination Services



Satisfaction with Communication across the Healthcare Team

At enrollment, almost half of the participating families were very satisfied with communication among health providers using the NSCH question, with the other half reporting somewhat satisfied. This rate is similar to the national rate at 58.8% reporting very satisfied (with the SD sample size too small to report valid).[6] At the post-survey, 82.6% reported ‘very satisfied’ with communication among healthcare providers, 13.0% somewhat satisfied, and 4.3% somewhat 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 significantly, with 56.5% of families indicating they were completely confident at the post-survey timepoint ($p<0.01$). Significant improvement was also found on level of satisfaction with providers working together to provide care, with 69.6% of families selecting ‘very satisfied’ ($p<0.01$). Improvements from enrollment to post-survey were also noted on the question about providers awareness of medical tests completed, with all families selecting the provider was usually or always aware of tests completed ($p<0.05$).

Figure 10. Perceptions of Healthcare Provider Communication



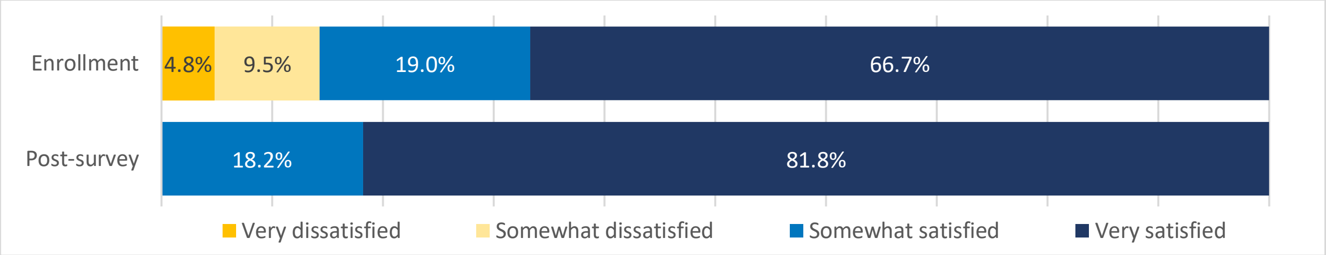
Satisfaction with Communication with Educational Entities

Eight of the 23 participants attended neither school nor childcare. Ten participants attended school only and five attended both school and childcare. Many (87.0%) reported that their child had either an individualized education plan (IEP) or an individualized family service plan (IFSP), both which provide necessary educational and early intervention supports to the child and family. Use of the IEP or IFSP by the healthcare team was assessed, with 90.0% of the families of children with an IEP/IFSP stating it was used to talk with the child's school or support team about his/her educational goals. Few families (25.0%) indicated the IEP/IFSP was used when the child's healthcare needs changed, and only one family selected that the IEP/IFSP was used every time the child is seen by the healthcare team.

Sanford MyChart

Sanford MyChart, the electronic patient medical record portal, is another method of communication between the family and healthcare providers. At enrollment, 21 of the 23 families had accessed the Sanford MyChart system in the past 12 months to review their child's records, and at the one-year timepoint 22 of 23 reported use of Sanford MyChart in the past year. Satisfaction with MyChart as a tool to manage the child's healthcare increased substantially from enrollment, with all families indicating either somewhat or very satisfied at the post-survey timepoint (Figure 11).

Figure 11. Satisfaction with Sanford MyChart

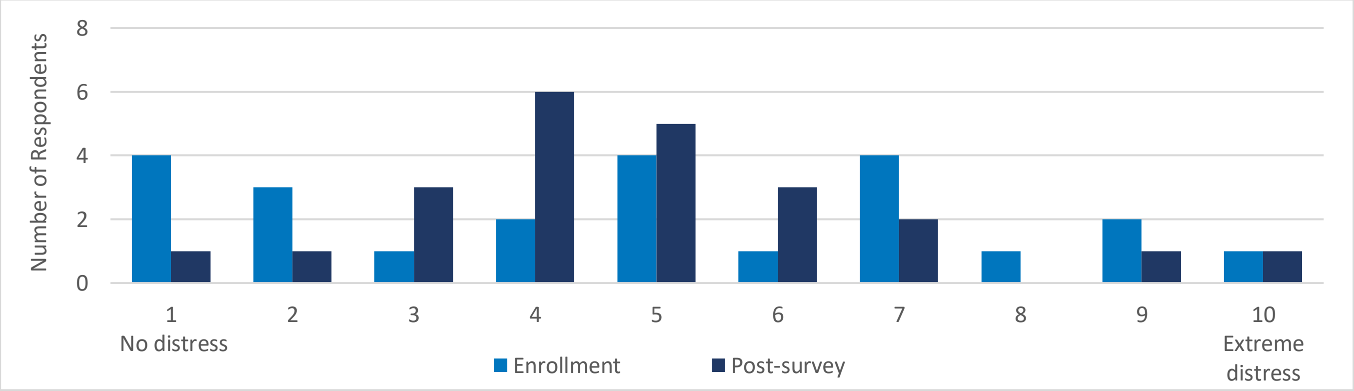


Family Needs

Parental Distress

Parents of CMC (as well as other family members) provide immense levels of medical care to their child. The physical, social, psychological, and financial toll of this often leads to significant distress.[8-10] Families were asked if the healthcare team inquired about how the child's condition(s) affects the family. At enrollment, only four respondents indicated that a member of the healthcare team had asked about family impact. This improved by the post-survey timepoint to eight respondents indicating that a member of the healthcare team had asked about family impact, with 11 families selecting 'no' and four families '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 Figure 12, responses were diffuse across both timepoints. At enrollment the mean score was 4.8 (SD 2.8) among the 23 respondents, and the mean score was 4.8 (SD 2.1) at post-survey, which was not a statistically significant difference.

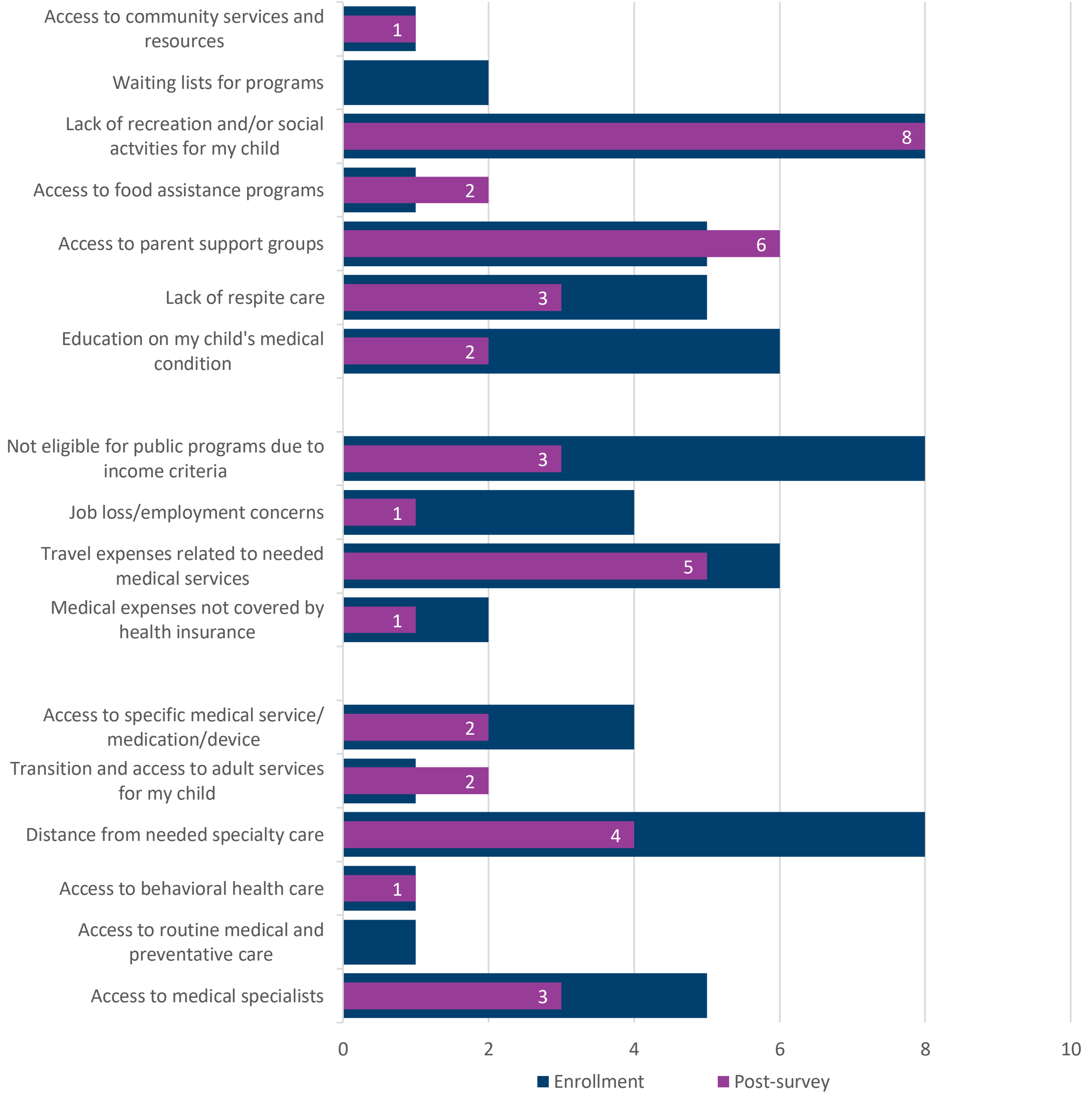
Figure 12. Frequency of Reported Level of Distress, Scale 1 to 10



Challenges

Families were asked about challenges in the areas of medical care for the child or family, financial concerns and community resources. Four families indicated no challenges in any area at enrollment, and six families indicated no challenges in any area at post-survey. Needs were examined from enrollment to post-survey, with fewer families identifying unmet needs across nearly all areas. Distance to specialty care, program eligibility, and education on the child's medical condition were much less commonly noted. Interestingly, two challenges were identified more at post-survey – transition and access to adult services for my child and parent support groups. The most frequently identified challenges remaining at the post-survey timepoint were lack of social or recreational activities for the child and access to parent support groups (Figure 13).

Figure 13. Identified Medical, Financial, and Community Resource Challenges

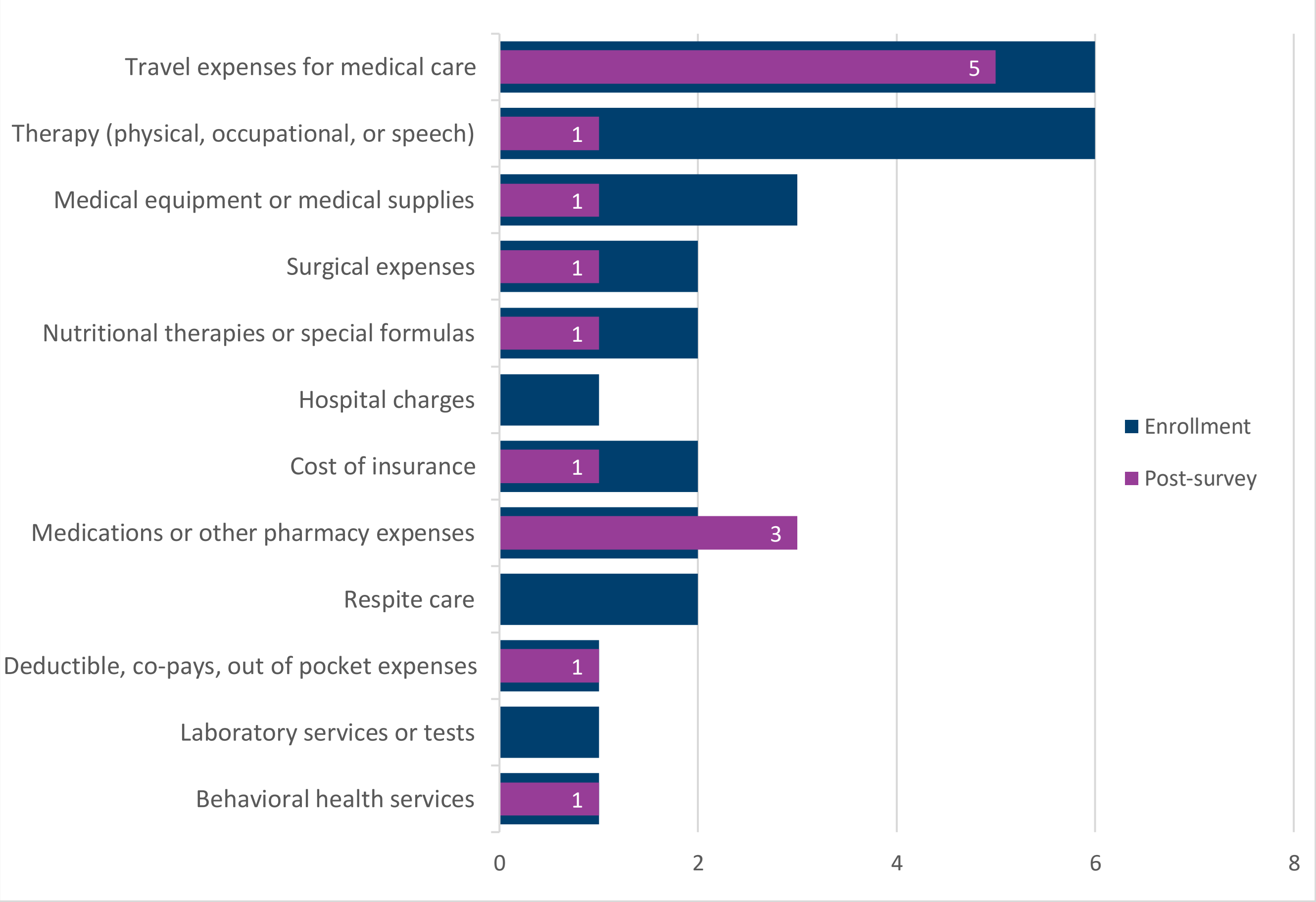


Financial Impacts

All participating families were asked if they had problems paying for their child's medical or other healthcare 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 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 in financial resources, and navigating medical systems to enhance efficiencies. At enrollment, three (13.0%) families acknowledged struggling to pay medical bills using the NSCH standard question. All enrolled children have Medicaid as a primary or secondary insurance. Insurance type may influence financial burden for families. At the post-survey timepoint, only one of the families reported having problems paying for their child's medical or healthcare bills.

A question asked enrolled families about specific services that create a significant financial burden. At enrollment, 12 families identified one or more areas that were a financial burden, and at post-survey only nine of the 22 families noted an area that was a burden. Figure 14 shows that travel expenses, and medications or other pharmacy expenses were the most frequently selected at the post-survey timepoint.

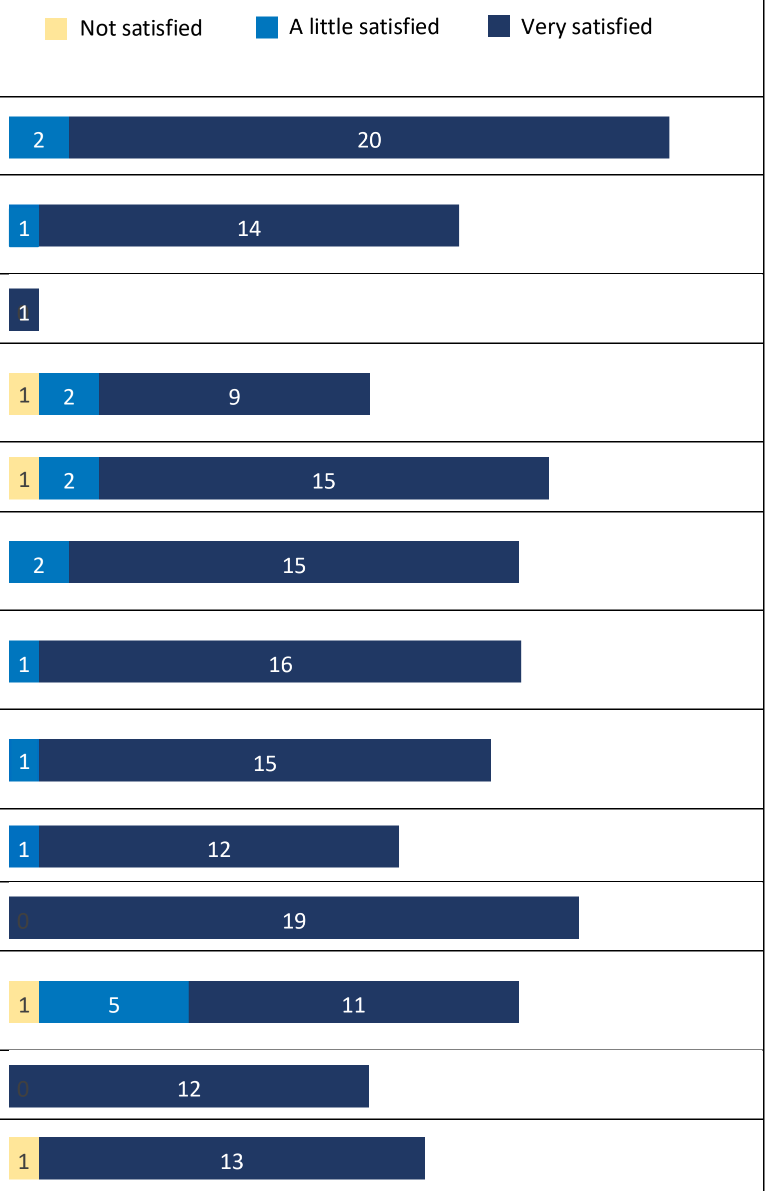
Figure 14. Type of Health-related Service that cause Significant Financial Burden



Satisfaction with the Sanford Patient Navigation Program

Families were asked to select their level of satisfaction with the assistance received from the RN Patient Navigator or other staff of the Patient Navigation Program for a variety of care coordination services. As shown in Table 2, the most common need for assistance was coordinating medical appointments, knowing who to call with questions, and helping the family feel less overwhelmed with the child's health issues. Levels of satisfaction with services were high across the various care coordination activities, and particularly in those services that were rated as the most frequent needs.

Table 2. Need and Satisfaction with Care Coordination Services Provided, Post-survey



	Number who reported needing assistance with this activity	Not satisfied	A little satisfied	Very satisfied
Coordinating medical appointments	22		2	20
Helping you understand medical instructions for your child's care	15		1	14
Getting transportation to the doctor's office	1			1
Assisting with financial concerns related to getting the care your child's needs	12	1	2	9
Feeling less overwhelmed by your child's health issues	18	1	2	15
Encouraging you to talk to the doctor about your child's health concerns	17		2	15
Getting the health information you need related to your child's care	17		1	16
Making you more involved in decisions about your child's healthcare	16		1	15
Helping you understand your child's medical tests or results	13		1	12
Knowing who to call when you had a question	19	0		19
Informing you about services in the community that are available to you and your child	17	1	5	11
Dealing with your child's health insurance	12	0		12
Helping you understand your child's health issues	14	1		13

Open-ended questions asked families to note the benefits of participating in the Patient Navigation Program over the past year and to provide suggestions on how to enhance the program in future years. Table 3 and 4 display all participant comments.

Table 3. Participant Comments on the Benefits of the Patient Navigation Program

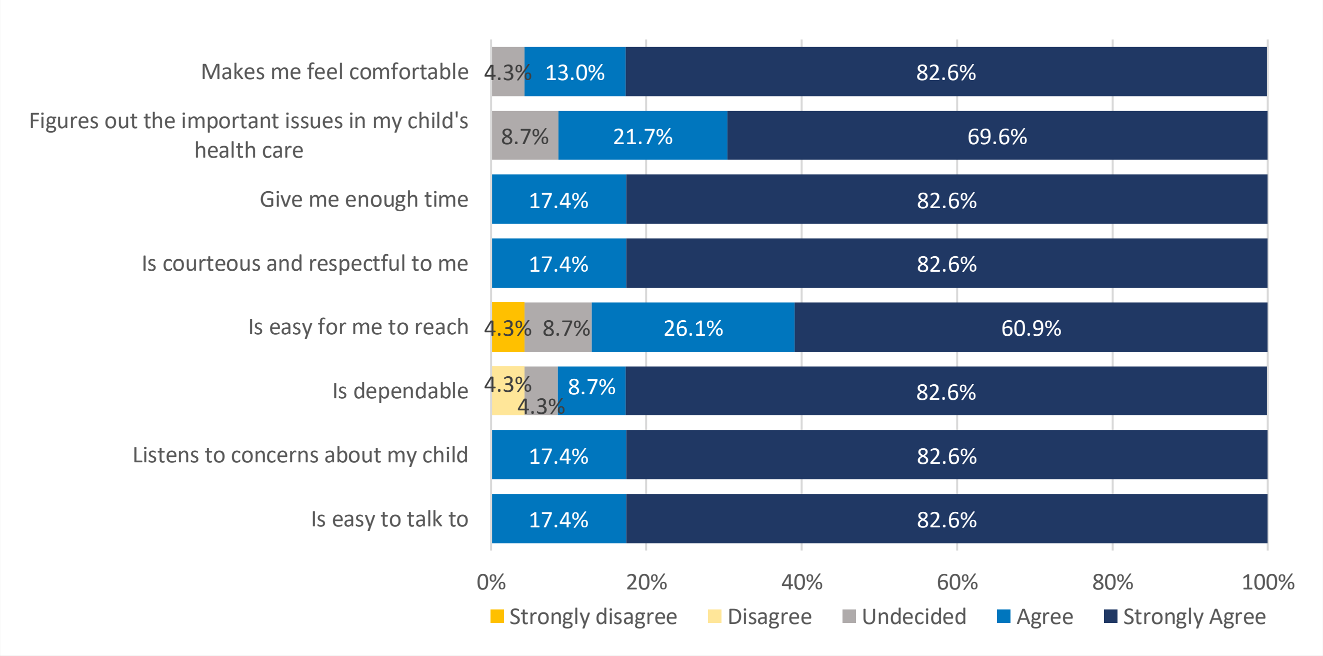
What aspects of the Patient Navigation Program were most helpful to you and your child?	• *Appointment reminders and calling to check in between appointments. Scheduling and rescheduling appointments.* • *Coordinating appointments and answering any questions I have or being able to connect me with someone who could.* • *Coordinating appointments and understanding medical terms, helping us with things we didn't understand.* • *Coordinating appointments.* • *For questions that weren't specific to a certain doctor. She was able to connect me to the right person.* • *Getting all her appointments together in the same day.* • *Getting more appointments put together.* • *Helping with appt. scheduling.* • *Helps in coordinating all my son's appointments. Helps to condense appointments into one day. Helps with programs/services I was not familiar with.* • *It is nice, if I have a question, I only have to talk to one person to get any answers or help I may need.* • *Knowing anything I need can always be answered by Tiffany or she tells me where to go to get my info - she's great!* • *LOVE Tiffany! It's been a very positive experience!* • *Making sure all follow-up and regular appointments were scheduled.* • *Our patient navigator has been wonderful! She has helped get us appts and lines them up on the same day, so we only make one trip. She really has been a lifesaver - and she is the sweetest person. I am comfortable visiting with her. She is also wonderful with our special needs child.* • *Phone check-ins to see if we needed anything between appts and coordinating multiple appts for one day to reduce travel.* • *Scheduling reminders, esp. with imaging tests.* • *The most helpful was knowing I didn't have to worry about a thing. Juggling all the appointments and stuff was difficult until Tiffany came into the picture. She has released so much stress off my plate.* • *Tiffany has been phenomenal. I am less stressed out and have had the energy and time to focus on my son and advocate for him because of her help! She finds joy and celebrates successes with us as well as comforts and shows empathy during the hard times! We love her!* • *Tiffany helped me not miss a couple important appointments. She was also very helpful in trying to figure out the best thing to do about vaccines.* • *Was very helpful helping with appointments and getting them moved when needed.*

Table 4. Suggestions to Improve the Patient Navigation Program

What aspects of the Patient Navigation Program could be improved?	• *Communication-unable to email or contact our navigator directly through MyChart. There were many times my navigator was looking into something, but we didn't hear back for quite some time.* • *Everything is amazing already - no change needed.* • *Get involved with the patient right after being discharged from the NICU.* • *Giving RN navigator the ability to message on MyChart.* • *Honestly, I've got nothing that comes to mind for improvements!* • *I really don't know I'm so blessed with* [child's name] *healthcare teams I never want for much.* • *I think the program is pretty good as is.* • *I wish I could send a message directly to Tiffany on Sanford MyChart.* • *I would like the option to be able to message her directly through my Sanford chart.* • *I'm not sure - I appreciate all she helps me with.* • *I'm not sure anything needs improvement in my case.* • *Providing more resources, parent groups, connections to programs he can be in.* • *Understanding/awareness of the variety of things they could help us with; maybe this was mentioned at first, but a reminder.* • *Wish we had it sooner.* • *This program would have been more helpful to me when we were discharged from the NICU than now. I have a good grasp on her health care now.* • *Would be nice if we could have her on MyChart instead of having to go through a doctor to send her a message.*

Participants were asked to rate the quality of service provided by the Sanford RN Patient Navigator, with a focus on family-centered behaviors and ease of access and communication between the navigator and the family. Figure 14 shows that levels of satisfaction were very high across all facets assessed. The lowest rated was “is easy for me to reach”, which still had a rate of agreement at 87%. Based on other survey responses, inability to message the navigator on MyChart may have impacted this specific rating.

Figure 14. Satisfaction with the Quality of Service, Post-Survey



Families were asked to provide additional comments to help us understand their experience. Nine provided comment, as presented in Table 5.

Table 5. Additional Comments from Families

Additional Comments on Experience	• *Again, would be a great service for those medically complex kids getting discharged from the NICU, we have a good grasp on my child's issues as we have been doing it for 3+ years now.* • *Amazing, so so grateful!* • *I'm so thankful they have programs like this. It makes parenting a special needs child much less stressful. Great job on helping us out!!* • *Love it!* • *Never get rid of this program! (or Tiffany)* • *Telemedicine would be great to have to cut down on how often we have to travel.* • *This program has helped my family so much and I greatly appreciate everything.* • *Tiffany was amazing and helped us with everything we needed! I had no worries when I called her to help.* • *Very helpful.* • *We are very happy here and I'm encouraging my family to come here.*

Summary

The Sanford Patient Navigation Program has served over 50 families to date, providing care coordination services to patients and families, addressing unmet needs, and improving communication across the healthcare team. This report shares feedback from 23 families one year after participating in the program, demonstrating significant improvements, pre- to post-program, in several important areas. In summary, parents of children with medical complexity involved in this study reported far fewer unmet needs just one year after enrolling in the program. Families also noted a overall high level of satisfaction with the quality of healthcare that their children received as a result of involvement with the Sanford Patient Navigation Program.

- More families indicated they received care in a medical home, that is, care that is "accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective."[3]
- More families reported that they are able to access the healthcare their children need when they need it.
- More families reported shared decision-making with their healthcare teams. Fundamental to shared decision-making is having a written plan of care in place, a plan that is shared among healthcare providers and children's parents, either in paper or electronic form. A significant increase was noted in family awareness of the shared plan of care, with only 17% of families reporting awareness of the plan on the pre-survey, compared to 74% at the post-survey.
- More families described the care of their children as effectively coordinated. Parents felt that extra help was provided by their healthcare teams when needed it and that their children's health providers communicated regularly with each other.
- Quality of services provided were rated very high across all facets assessed. Parents' noted interactions with the Sanford RN Patient Navigator very positively. Comments such as "our patient navigator has been wonderful" and "she has been phenomenal" were prevalent.
- Satisfaction with the Sanford MyChart tool to manage children's healthcare needs, increased substantially from pre- to post-program.

Recommendations

Findings also point to some key areas to further assist families through the Sanford Patient Navigation Program. We offer the following recommendations based on the families' responses:

- Numerous program participants said they were unable to use Sanford MyChart to communicate with the Patient Navigator. Families see this tool as beneficial to communication with the healthcare team. Improved access to staff through Sanford MyChart needs to be addressed as the program continues.
- Parents indicated some concerns with transitions. More attention should be focused on enrolling program participants earlier (directly after discharge from the NICU) and on moving children to adult services.
- Embedded within these generally positive findings is a troubling absence of assessment on how these children's conditions impact their families. Specifically:
    - Parents' level of distress remained unchanged throughout the program (mean score 4.8 pre-program and 4.8 post-program).
    - At the start of the program, only four of the 23 respondents indicated that a member of the healthcare team had asked about how the child's condition affects the family. After one full year of program operation, this number increased to eight, with roughly two of every three families reporting the healthcare team neglected to inquire about family impact.
- Families noted a few specific challenges that remain at the one-year time point including lack of access to parent support groups, limited social/recreational activities for children outside the family, financial burden specific to pharmacy costs and travel expenses, limited use of the IEP/IFSP by the healthcare team, and ongoing support needed to feel less overwhelmed by their children's health issues. Consider if any of these challenges can be further addressed through specific actions of the Sanford Patient Navigation team.

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For Study Staff Only

Participant ID: ____________________

SANFORD
Children's

Patient Navigation Program for Children with Complex Medical Conditions

One-Year Survey

Congratulations on your first year of participation in the Patient Navigation Program! This survey is designed to gather information about your family's health care experiences as you have worked with the RN Patient Navigator in the past year. 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 one-year survey will help us improve services for children with complex medical conditions and their families.

Thank you once again for your time and input.

SOUTH DAKOTA DEPARTMENT OF HEALTH

SOUTH DAKOTA STATE UNIVERSITY

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. **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?	☐	☐	☐	☐

2. **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

3. How confident are you that if or when your child has a new health care provider, 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

4. 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

5. **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 in order to avoid unnecessary testing?
   - ☐ Never
   - ☐ Sometimes
   - ☐ Usually
   - ☐ Always

6. 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

7. 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

8. **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

9. **In the last 12 months**, have you accessed Sanford MyChart for information about your child's visits and health care?
   - ☐ No
   - ☐ Yes → How satisfied are you with Sanford MyChart as a tool to manage your child's health care?
     - ☐ Very dissatisfied
     - ☐ Somewhat dissatisfied
     - ☐ Somewhat satisfied
     - ☐ Very satisfied

10. **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

11. Has your child had a telemedicine visit with a health care provider in the past? *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 or healthcare team member in another location.

    ☐ Yes, a telemedicine visit from my home with a provider or another member of the healthcare team.

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.

12. Does your child have a shared plan of care?

    ☐ No *(Please skip to question 15.)*
    ☐ I don't know *(Please skip to question 15.)*
    ☐ Yes→ How satisfied are you with your child's shared plan of care?
        ☐ Very dissatisfied
        ☐ Somewhat dissatisfied
        ☐ Somewhat satisfied
        ☐ Very satisfied

13. 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.	☐	☐	☐

14. An emergency plan is part of the shared plan of care document. The emergency plan includes special considerations that all people caring for your child should know if there is an urgent health situation. For example, the emergency plan might state how your child lets you know he or she is in pain, or how to communicate with your child if he or she can't hear or speak. Families often bring the emergency plan when they take a child to an emergency room or urgent care clinic.

    Has your child's health care team created an emergency plan for your child?

    ☐ No
    ☐ Yes
    ☐ I don't know.

Assistance with Managing Your Child's Care

15. **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.]*
  ☐ Sanford RN Patient Navigator
  ☐ 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: ______________________________

16. **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

17. 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?	☐	☐	☐	☐

18. **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

19. Does your child have an IEP or IFSP?

   An individualized education plan (IEP) is a written document that describes the necessary educational supports and services needed in the school setting for eligible children ages 3 to 21. This is generally developed by school personnel and should include input from the student, family, and/or other health care team members. An individualized family service plan (IFSP) is a written document that describes the necessary early intervention services and supports for your child (birth to age 3) and family in the home setting. The IFSP is typically developed by the professionals involved in assessment of your child's needs and should include input from the family, and other health care team members.

   - ☐ No
   - ☐ Yes → Which of the following describes the use of your child's IEP or IFSP? *Check all that apply.*
     - ☐ It is used every time my child is seen by their health care team.
     - ☐ It is used when I talk with my child's school or support team about his/her educational goals.
     - ☐ It is used when my child's health care needs change and the plan is updated.
     - ☐ An IEP or IFSP was created but has not been used in more than 12 months.

20. **In the last 12 months**, did your child attend school or childcare?

   - ☐ No *(Please skip to question 22.)*
   - ☐ Yes, school only.
   - ☐ Yes, childcare only.
   - ☐ Yes, both school and childcare.

21. **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

Satisfaction with the Patient Navigation Program

22. Please rate your level of satisfaction with the help provided to you or your child by the Sanford RN Patient Navigator or Patient Navigation Program for each listed service:

	Not satisfied	**A Little Satisfied**	**Very Satisfied**	**We didn't need help with this.**
a. Coordinating medical appointments	☐	☐	☐	☐
b. Helping you understand medical instructions for your child's care	☐	☐	☐	☐
c. Getting transportation to the doctor's office				
d. Assisting with financial concerns related to getting the care your child's needs	☐	☐	☐	☐
e. Feeling less overwhelmed by your child's health issues	☐	☐	☐	☐
f. Encouraging you to talk to the doctor about your child's health concerns	☐	☐	☐	☐
g. Getting the health information you need related to your child's care	☐	☐	☐	☐
h. Making you more involved in decisions about your child's health care	☐	☐	☐	☐
i. Helping you understand your child's medical tests or test results	☐	☐	☐	☐
j. Knowing who to call when you had a question	☐	☐	☐	☐
k. Informing you about services in the community that are available to you and your child	☐	☐	☐	☐
l. Dealing with your child's health insurance	☐	☐	☐	☐
m. Helping you understand your child's health issues	☐	☐	☐	☐

23. What aspects of the Patient Navigation Program were the most helpful to you and your child?

____

____

____

24. What aspects of the Patient Navigation Program could be improved?

____

____

____

25. Please rate your level of agreement with the quality of service provided by the Sanford RN Patient Navigator for each item below:

	Strongly Disagree	**Disagree**	**Undecided**	**Agree**	**Strongly Agree**
a. Is easy to talk to	☐	☐	☐	☐	☐
b. Listens to my concerns about my child	☐	☐	☐	☐	☐
c. Is dependable	☐	☐	☐	☐	☐
d. Is easy for me to reach	☐	☐	☐	☐	☐
e. Is courteous and respectful to me	☐	☐	☐	☐	☐
f. Gives me enough time	☐	☐	☐	☐	☐
g. Figures out the important issues in my child's health care	☐	☐	☐	☐	☐
h. Makes me feel comfortable	☐	☐	☐	☐	☐

About You and Your Child

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

Number of people: ____________________________

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

Number of children (age 18 and younger): ___________________________

28. 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

29. 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

30. 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

31. 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

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

Medical care for child or family

☐ 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.**

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

☐ No
☐ Yes

34. Among the services listed below, which, if any, create a significant financial burden for your family? *Please check all that apply.*

☐ Cost of insurance (premiums)
☐ Deductible, co-pays, out of pocket expenses
☐ Hospital charges
☐ Medications or other pharmacy expenses
☐ Nutritional therapies or special formulas
☐ Laboratory services or tests
☐ Medical equipment or medical supplies
☐ Surgical expenses
☐ Therapy (physical, occupational, or speech)
☐ Behavioral health services
☐ Respite care
☐ Travel expenses for medical care (e.g., transportation, lodging, meals)
☐ Other: ____

35. Is there anything else you would like us to know about your experience with the Sanford Patient Navigation Program?

____

____

____

____

____

Thank you for completing the survey!

Please place the survey in the addressed, postage-paid envelope and return it to the Sanford RN Patient Navigator or place the envelope in the mail.

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.