Children and Youth with Special Health Needs

Year 1: Needs Assessment Report

JANUARY 2016

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Summary of findings

According to the 2011-2012 National Survey for Children with Special Health Care Needs, 18.5 percent of Minnesota children and youth (0-18 years old) have special health care needs.[1] Children with special health care needs require access to a variety of specialized services, and families may face a variety of barriers in receiving such services.

In 2014, the Minnesota Department of Health (MDH) was awarded a three-year federal grant to implement a more coordinated system of services and supports for children and youth with special health needs (CYSHN) and their families. This project seeks to increase stakeholder engagement and collaboration, as well as increase families' knowledge of the services and supports available to them.

MDH contracted with Wilder Research (Wilder) to conduct an evaluation of the project. In the first year of the grant the evaluation focused on a baseline assessment of CYSHN, which included the following activities:

- A web survey of project stakeholders
- A web survey of parents of CYSHN
- One-on-one interviews with parents of CYSHN
- An analysis of administrative data on the outcomes of CYSHN in Minnesota, and the gaps in services that these children and families face

A summary of findings from year one of the evaluation is outlined below.

Stakeholder engagement

- **Stakeholders and parents want to share their expertise to make impactful system improvements for CYSHN and their families.** In response to an open-ended question, stakeholders and parents gave a variety of reasons for becoming involved in the grant. One-third of stakeholders said they wanted to help children and youth with special health needs and their families; and over one-quarter (27%) said they wanted to help create more integrated systems of care. Both groups expressed the desire to share their expertise.

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[1] National Survey of Children's Health. NSCH 2011/12. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved [01/13/16] from www.childhealthdata.org.

- **While respondents are passionate about creating better outcomes for CYSHN and their families, they expressed skepticism that the grant will bring change to the health care system.** When speaking about their expectations for the grant, several stakeholders felt some skepticism about the ability of the Workgroup to affect actual change. They said that while it is easy to define a problem and possibly even a solution, it is much harder to actually put those solutions in to effect. Stakeholders expressed a strong desire to go the extra mile to implement new strategies that will make the system easier to navigate for CYSHN and their families.

- **Stakeholders want more clarity around the grant, including their role in it.** Part of stakeholders' skepticism about the grant may come from a lack of clarity about the grant and its goals, as well as the purpose of the Stakeholder Workgroup. When asked whether they agree or disagree with a series of statements, the majority of respondents (on most items) were unsure. For example, when asked if the grant is implementing the right strategies to ensure success, 75 percent of respondents said they did not know. In another series of statements, over three in ten stakeholders disagreed that they have a clear sense of what the Stakeholder Workgroup is trying to accomplish (31% disagree, 31% unsure) or their roles and responsibilities in the group (32% disagree, 44% unsure).

- **Stakeholders feel that time, money, and overlapping initiatives all pose challenges to the success of the grant.** Like many other grant initiatives, respondents feel that the main challenges for the Systems Integration Grant are logistical—a lack of time and money to implement the grant, as well as having to navigate a lot of systems and bureaucracy. In addition, several respondents felt that it was challenging to balance the work of this grant with that of other initiatives happening nationally. A couple of respondents mentioned that there seems to be overlapping work, and it would be more efficient to marry similar efforts.

Services received and needed

In addition to getting initial feedback from stakeholders, a Gaps Analysis survey and parent interviews looked at services—both used and needed—for CYSHN in order to establish a baseline picture of what they and their families experience in the system.

- **In the past 12 months, parents were most likely to receive services in a health care setting, as opposed to through their home or communities.** As found in the Gaps Analysis survey, at least half of clients reported receiving the following services in the past 12 months: doctor or primary care appointments (96%), case management or care coordination (64%), therapy (occupational (OT) or physical (PT); 63%), medication management (54%), and mental health counseling (50%). Of the services respondents and their children had received, they were *least* likely to include day treatment for mental health (18%), personal support or companion services (15%), a home health aide or visiting nurse (14%), or financial assistance (13%).

- **Parents across all surveys indicated that their children have access to a regular provider or clinic for routine or preventative care, as well as care for when their children are sick**. Most parents in the parent interviews (95%) and the Gaps Analysis survey (97%) said that their child has a place to go for routine care to stay healthy, and this is most often a clinic or doctor's office (86%). Similarly, 88 percent of parents have a place to go for help when their child is sick, which is most often a doctor's office or clinic (93%).

- **Parents were easily able to access their primary care appointments, whereas other services were more difficult to access.** Of the caregivers in the Gaps Analysis survey who had gone to a primary care appointment in the past year, 64 percent said this was a very easy service to access—the highest of any service. Of the other services that parents received, they had the most difficulty accessing respite care (100%), assistive technology, specialized equipment, and home modifications (60%), Personal Care Assistants (PCAs; 48%), medication management (44%), and skills group and/or skills training (40%).

- Of the services that parents felt they needed, but had not received, they had the most difficulty with services that are typically received in the community or at home. Three in ten (29%) parents said they felt they needed respite care, but were unable to get it; 22 percent said the same about caregiver or family training; and 18 percent each had a difficult time accessing PCAs and skills groups and/or skills training. The most common reasons that parents were unable to access these services were that the services were not located near them, they lacked the time needed to access services or the process was too confusing, or they could not afford to access the service (i.e., high co-pays, no sliding fee scale).

- **Although many parents utilize care coordination or case management services, few parents felt it was the most valuable service.** Nearly two-thirds of parents reported getting these services in the past 12 months, with any additional 4 percent who needed them, but were unable to get them. Of those parents and children receiving these services only 2 percent felt it was the most helpful service, while 27 percent felt these services were not helpful.

Experiences with health care providers

Despite some difficulty in accessing services, caregivers of children and youth with special health needs had very positive experiences with their primary care providers, which may not be surprising given the frequency and ease with which they access this service.

- **The majority of parents felt that their health care providers spent enough time with them.** In both the Gaps Analysis and parent interviews, the majority of parents felt that their doctor had spent enough time with them and their child (parent interviews: 68% always or usually; Gaps Analysis: 61% always or almost always).

- **Parents generally feel that they are able to engage with their health care providers and that their input is valued:** In the Gaps Analysis survey, over half of parents (56%) said that their health care providers always or almost always encourage them to ask questions. Similarly, half of parents in the parent interviews felt that their input was always valued, while another third said that their input was usually valued. There were some slight differences in terms of race on this question; Hispanic respondents were more likely than other groups to say that their input was always valued (five respondents), while Somali parents were the least likely to say their input was always valued (one respondent).

- **Overall, parents felt that their health care providers were sensitive to their cultural values.** In the Gaps Analysis survey, 61 percent of parents said their health care providers are always or almost always sensitive to their family's values and customs; 34 percent felt this was sometimes the case.

Introduction

In 2014, the Minnesota Department of Health (MDH) was awarded a three-year State Implementation Grant (SIG) by the U.S. Department of Health and Human Services, Health Services and Resources Administration (HSRA) to achieve a comprehensive, coordinated, and integrated state and community system of services and supports for children and youth with special health needs (CYSHN) and their families.

This project, titled the *Minnesota CYSHN Systems Integration Project,* has three main goals:

1. Increase stakeholder engagement and partnerships within statewide initiatives.
2. Increase cross-systems integration through providing more effective care coordination services for CYSHN and their families.
3. Increase the knowledge of services and supports available for CYSHN through the enhancement of a "CYSHN Navigator" (shared resource) for providers and families of CYSHN.

In order to determine what progress is being made toward these goals, MDH contracted with Wilder Research (Wilder) to conduct an evaluation of the project. With support from MDH staff and the project stakeholders, Wilder developed a preliminary set of process- and outcome-related research questions. These questions, which can be found in the Appendix, are based on the "Project Evaluation Plan" provided to Wilder by MDH, as well as feedback from the first stakeholder meeting in February 2015. Participants were asked to talk about what they would like to see happen in the future under each of the three grant goals.

In addition to developing research questions, Wilder and the Project Lead team conducted: 1) a web survey of the Stakeholder Workgroup, 2) a web survey of the Parent Workgroup, 3) one-on-one interviews with parents of children and youth with special health needs; and 4) an analysis of the gaps in services that children and youth with special health needs face in Minnesota. The methods used in each of these activities are also outlined below.

Research methodologies

In order to determine what progress is being made toward the goals of the State Implementation Grant, MDH contracted with Wilder Research (Wilder) to conduct an evaluation of the project. In year one, the evaluation focused on four main activities related to the baseline assessment:

- **A web survey of the Stakeholder Workgroup:** Wilder administered a web-based survey to members of the Stakeholder Workgroup to learn more about their expectations for the Workgroup, as well as the overall grant. A survey link was sent to 26 unique email addresses, provided to Wilder by MDH. A total of 16 stakeholders took the survey, for a response rate of 62 percent; although not all respondents answered every question.

- **A web survey of the Parent Workgroup:** Wilder administered a web-based survey to members of the Parent Workgroup in order to learn more about their leadership experiences, and their expectations for the Workgroup and overall grant. A survey link was sent to nine unique email addresses, provided to Wilder by MDH. A total of five parents took the survey, for a response rate of 56 percent; although not all respondents answered every question.

- **One-on-one interviews with diverse parents of children and youth with special health needs:** A total of 22 interviews were conducted with African American (n=5), Hispanic (n=6), Hmong (n=6), and Somali (n=5) families in their primary language. Interviews were conducted by parent advocates from the PACER Center. The Project Leadership Team collaborated on the data collection instrument, and parent advocates provided guidance on the questions. PACER staff were also briefed by Wilder on how to conduct a social science interview. A PACER staff member sent completed, de-identified forms back to Wilder for analysis.

- **Gaps Analysis survey:** In the spring of 2015, Wilder conducted a Gaps Analysis study, commissioned by the Minnesota Department of Human Services, to gather information about Minnesota's publicly-funded home- and community-based service systems and the continuum of mental health services. The survey focused on service availability and use, the quality of services, as well as service gaps. CYSHN are included in this study and were identified as youth, ages 0-17, living with mental health conditions and/or disabilities. Ninety-eight caregivers of CYSHN responded to the online Gaps Analysis survey. Caregivers and their children were identified by Minnesota Health Care Program enrollment records and consumer advocacy organizations.

Stakeholder engagement

As one of the main goals of the grant is to increase stakeholder engagement and partnerships within statewide initiatives, MDH staff gathered a group of stakeholders to provide input on the project and identify areas of need facing CYSHN and their families.

Grant partners

Several key stakeholders provided support and input into the needs assessment and grant writing process. They were involved by attending meetings, participating in conference calls, and reviewing drafts. The agencies and organizations that provided support are listed below:

- Family Voices of Minnesota
- Parent Advocacy Coalition for Educational Rights (PACER) Center – Minnesota’s Family-to-Family Health Information Center
- CYSHN Parent Workgroup
- Minnesota Department of Health
- Minnesota Department of Human Services
- Minnesota Department of Education
- Minnesota Chapter of the American Academy of Pediatrics
- Minnesota State Interagency Committee (MnSIC)
- National Help Me Grow Lead Team

In addition to these groups, the project also has a Stakeholder Workgroup, which is made up of representatives from each of the groups above and convenes on a quarterly basis to discuss the goals and progress of the grant; as well as a Project Leadership team, made up of staff from MDH, Wilder, Family Voices of Minnesota, and PACER Center.

Partner feedback

Wilder administered a web-based survey to members of both the Stakeholder and Parent Workgroups on order to learn more about their expectations for the grant. A total of 16 stakeholders and five parents took the survey. Findings from each survey are outlined below; additional data tables can be found in the Appendix.

Stakeholders and parents want to share their expertise to make impactful system improvements for CYSHN and their families.

In an open-ended question, stakeholders gave a variety of reasons for becoming involved in the project, with one-third saying they wanted to help children and youth with special health needs and their families. Over one-quarter said they wanted to help create more integrated systems of care (Figure 1).

1. Reasons for getting involved in the Stakeholder Workgroup (N=15)

	N	%
To help CYSHN and their families	5	33%
To help create more integrated systems of care	4	27%
To share expertise	3	20%
Because it applies to something specific in my work	3	20%
Other	2	13%

Note: *Percentages add up to more than 100, because stakeholders were able to give more than one reason.*

> *I have knowledge and experience that I believe will be valuable to the group, and I am committed professionally to improving coordination of care for CYSHN. – Stakeholder Workgroup member*
>
> *I care very much about services for families of children and youth with special health needs and want to see improvement. I think this project has a great opportunity to improve services. – Stakeholder Workgroup member*

Similarly, when parents were asked why they had become involved in the Parent Workgroup, they said that they wanted be a voice for other parents struggling to navigate the system.

> *When I was a single mother with a child with special health needs, I was in survival mode. I learned as I went along and have since found out that I am fighting the same fight that parents in my community were fighting when I was in school. I want this to change. It should not be this difficult! – Parent Workgroup member*
>
> *I believe that voices who are in outstate MN are often times not heard. I wanted to help be a voice that is heard. – Parent Workgroup member*
>
> *I am dedicated to building a strong parent network for families of CYSHN and hope to bring more family voices to the table in design, planning, and evaluation of all programs and policies that affect CYSHN. – Parent Workgroup member*

Parents also expressed a great deal of passion about their advocacy and felt confident in their ability to lead and be the voice that other parents may need. All five parents rated their energy and enthusiasm to lead as excellent, and all were also very involved with CYSHN issues in their community (Figure 2).

2. Factors related to parent leadership (N=5)

Currently, how would you rate your...	Excellent	Good	Okay
Energy and enthusiasm to lead?	5	0	0
Involvement in planning the care your child gets outside of your home (e.g. in the school or in the community)?	4	1	0
Ability as a parent leader to make an impact on the issues related to CYSHN that are important to you?	3	2	0
Ability to find resources to help make things better for your family or families like yours?	3	1	1
Confidence as a parent leader?	2	3	0

Note: *Respondents were asked to rate their responses on the following scale: Excellent, Good, Okay, Poor, or Very Poor. No respondents provided a Poor or Very Poor rating for any item; therefore those columns are excluded from the table above.*

While respondents are passionate about their work, they expressed skepticism that the grant will affect change to the health care system.

Respondents were asked about their expectations for the grant, as well as the Workgroup. Three in ten stakeholders said they wanted better outcomes for CYSHN and their families, while another three in ten said they wanted more shared information and alignment with other systems (Figure 3). When speaking about their expectations, several stakeholders expressed skepticism about the ability of the Workgroup to affect actual change. They said that, while it is easy to define a problem, and possibly even a solution, it is much harder to actually put those solutions in to effect. Stakeholders expressed a strong desire to go the extra mile to implement new strategies that will make the system easier to navigate for CYSHN and their families.

3. Expectations about the primary effect of the grant (N=14)

	N	%
Better outcomes for families and CYSHN	4	29%
Shared information/Alignment with other systems	4	29%
Achieve grant goals	3	21%
No effect	2	14%
Other	3	31%

Note: *Percentages add up to more than 100, because stakeholders were able to give more than one reason. "Other" responses include: "I'm not sure yet," "We continue to grow as a clinic," and "We will need to be aware of the SIG."*

> *If we stop at the point of mapping and identification of the problems, I am not sure the grant will have accomplished anything new (similar to past identification of barriers, problems). That would feel negative. A positive would be implementing some of the strategies identified to change outcomes for CYSHN. I am somewhat unclear about the ability of this group of stakeholders to do more than provide input from each group's perspective – implementation will be the work of MDH staff and will also require advocacy related to policy. – Stakeholder Workgroup member*
>
> *We have identified a lot of needs and opportunities. I think the workgroup needs to go a step further and assist with or help identify ways to actually intervene - implement changes etc. It feels like we have collected a lot of the "whys" and identified strategies - I'd like to see the strategies put into action. – Stakeholder Workgroup member*

Stakeholders want more clarity around the grant, including their role in it.

Part of stakeholders' skepticism about the grant may come from a lack of clarity about the grant and its goals, as well as the purpose of the Stakeholder Workgroup. When asked whether they agree or disagree with a series of statements, the majority of respondents (on most items) were unsure. For example, when asked if the Systems Integration Grant is implementing the right strategies to ensure success, 75 percent of respondents said they did not know (Figure 4).

4. Opinions about the overall grant (N=16)

The Systems Integration Grant…	Strongly agree	Somewhat agree	Somewhat disagree	Strongly disagree	Don't know
Has the right partners involved in the work.	13%	56%	0%	0%	31%
Has the right leadership to succeed.	13%	25%	6%	0%	56%
Has taken on the right amount of work.	6%	25%	0%	0%	69%
Is progressing at the right pace.	6%	19%	13%	6%	56%
Is implementing the right strategies to ensure success.	6%	13%	0%	6%	75%

Additionally, no respondents strongly agreed they understood what the Workgroup was trying to accomplish or felt confident that it would achieve its goals. Like the questions around the grant, respondents were unsure how they felt about the progress of the Workgroup (Figure 5).

5. Opinions about the Stakeholder Workgroup (N=16)

	Strongly agree	Somewhat agree	Somewhat disagree	Strongly disagree	Don't know
The level of commitment among stakeholders is high.	13%	31%	6%	6%	44%
Stakeholders, overall, have a clear sense of their roles and responsibilities.	6%	19%	19%	13%	44%
I have a clear sense of what the CYSHN Stakeholder Workgroup is trying to accomplish.	0%	38%	25%	6%	31%
I am confident the Stakeholder Workgroup will achieve its goals and purpose.	0%	44%	19%	0%	38%

Stakeholders feel that time, money, and overlapping initiatives all pose challenges to the success of the grant.

Like many other grant initiatives, respondents felt that the main challenges for the Systems Integration Grant were logistical—a lack of time and money to implement the grant, as well as having to navigate a lot of systems and bureaucracy. In addition, several respondents felt that it was challenging to balance the work of this grant with that of other initiatives happening nationally. A couple of respondents mentioned that there seems to be overlapping work, and it would be more efficient to marry similar efforts.

> *There is a lot of similar work happening nationally. It will be challenging to balance the momentum of this group independently with the need to learn from the work of others. A primary challenge may be moving the ideas and expectations of stakeholders to a level of political influence that will actually make a difference. – Stakeholder Workgroup member*

Services received and needed

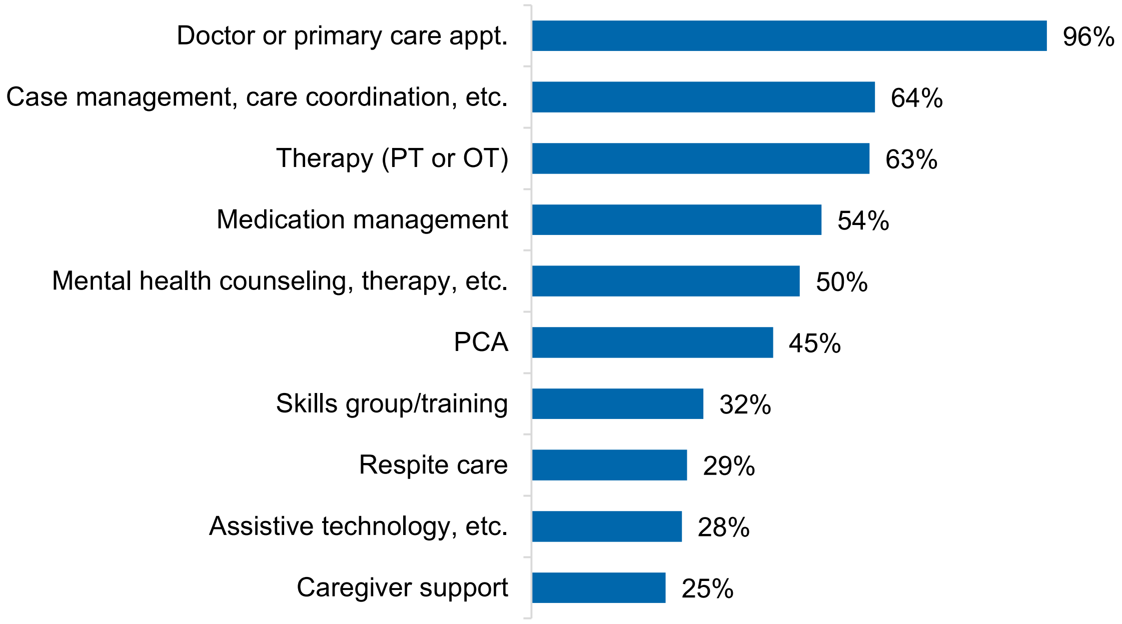
In addition to getting initial feedback from the workgroups, the Gaps Analysis looked at services—both used and needed—for CYSHN in order to establish a baseline picture of what they and their families experience in the system.

Services received in the past 12 months

The Gaps Analysis survey showed that, in the past 12 months, nearly all respondents indicated that their child had a doctor or primary care appointment (Figure 6). At least one-quarter of respondents received a variety of other services ranging from caregiver support to case management.

Less than one-quarter of respondent's children received transportation, day treatment for mental health, personal support or companion services, home health aide or visiting nurse, and financial assistance.

6. Services received in the past 12 months (N=98)



The services received in the past 12 months met some or all of their needs for 96 percent of respondents and their children (Figure 7).

7. How well does all the help received in the past 12 months meet your needs? (N=95)

	N	%
Meets all my needs	30	32%
Meets some of my needs	61	64%
Meets none of my needs	3	3%
Don’t know	1	1%

Most helpful services

The most helpful services respondents reported receiving were:

- Personal Care Assistant (PCA; 59%)
- Financial assistance (33%)
- Therapy (OT/PT; 19%)
- Assistive technology, specialized equipment, and home modifications (19%)

Fewer respondents reported the following services as most helpful: mental health counseling, therapy, or psychiatry (18%), medication management (17%), skills group and/or skills training (16%), respite care (14%), personal support or companion services (13%), a doctor or primary care physician appointment (12%), home health aide or visiting nurse (7%), transportation (5%), and case management, care coordination, or social worker services (2%). Day treatment for mental health or caregiver support/training were not reported as the most helpful service by any of the respondents who reported their child received those services in the past 12 months.

More than half of respondents indicated that the following services were very easy or somewhat easy to get: doctor or primary care appointment (91%), therapy (OT/PT; 88%), skills groups and/or skills training (60%), mental health counseling, therapy, or psychiatry (55%), and PCA (52%). Transportation, financial assistance, and care manager, care coordinator, or social worker services were somewhat easy for each of the respondents who reported these as the most helpful services.

The services that were most often reported as difficult to get include assistive technology, specialized equipment, and home modifications, personal support/companion services, home health aide or visiting nurse, and respite care. The main reasons for experiencing difficulty were: a lack of provider availability, respondent eligibility, a lack of qualified providers, and a dearth of services.

All respondents who found the following services to be most helpful, reported the quality of the services to be ‘good’ or ‘very good’: Assistive technology, specialized equipment, and home modifications, transportation, home health aide or visiting nurse, therapy (OT/PT), mental health counseling, therapy, or psychiatry.

Services needed, but unable to get

In addition, the Gaps Analysis survey showed that 49 respondents (52%) felt there are services their child needs, but they are unable to get them. The most frequently mentioned types of help needed, but not received include respite care (29%) and caregiver or family training/support (22%). Eight other types of help were reported by two to nine respondents as help they and their child needed, but were not getting (Figure 8). It should also be noted that no respondent indicated that doctor or primary care physician appointments were a type of help needed, but not received.

8. What type(s) of help are you unable to get, but think you need? (N=49)

	N	%
Respite care	14	29%
Caregiver or family training/support	11	22%
PCA (Personal Care Assistant)	9	18%
Skills groups and/or skills training	9	18%
Assistive technology, specialized equipment, and home modifications	8	16%
Personal support/companion services	7	14%
Crisis services	6	12%
Residential treatment for mental health	5	10%
Mental health counseling, therapy, or psychiatry	4	8%
Case manager, care coordinator, or social worker	2	4%

Note: *Percentages add up to more than 100, because caregivers were able to indicate more than one service.*

Slightly less than one-quarter of respondents indicated the reasons they and their child were not receiving needed services was due to:

- The service not being near them
- It was difficult to get (i.e. they lacked the time, the process was confusing)
- They could not afford it (i.e. high copays, no sliding fee scale)

Experiences with health care providers

An important aspect of providing quality care to children and youth with special health needs is ensuring that families are having positive experiences with their health care providers. The data below illustrate findings from both the Gaps Analysis survey, as well as the parent interviews.

The majority of parents have a regular health care provider

It is clear that, despite some difficulty in accessing specific services, caregivers of children and youth with special health needs had very positive experiences with their primary care providers. They are also well connected with health care facilities for both preventative and acute care needs.

Nearly all parents had a routine health care provider for their child's preventative health care needs (97% in the Gaps Analysis survey; 95% in the parent interviews), and most respondents (88%) in the Gaps Analysis survey indicated that they also have a place they go when their child is sick and they need advice. When their child is sick, respondents most often go to a doctor's office or clinic for advice (Figure 9).

9. Location of place to get advice about child's health (N=83)

	N	%
Doctor's office or clinic	77	93%
Urgent care	3	4%
Hospital Emergency Room	1	1%
Other health center	2	2%

Parents feel that their doctor spends time with them and values their input

Most respondents also felt that their health care providers spent enough time with them; 61 percent of respondents in the Gaps Analysis survey indicated that their child's health care provider always or almost always spent enough time with their family, and 68 percent of parents interviewed said the same.

Parents also felt that they are able to engage with their health care providers and that their input is valued. More than half of respondents in the Gaps Analysis survey indicated that their child's health care provider encourages them and their children to ask questions always or almost always (Figure 10).

10. Doctor encourages you or your children to ask questions (N=95)

In the past 12 months, how often did doctors and other health care providers encourage you or your child(ren) with special health needs to ask questions?	N	%
Always or almost always	52	56%
Sometimes	31	33%
Rarely	9	10%
Never	0	0%

Similarly, half of parents in the parent interviews felt that their input was always valued, while another third said that their input was usually valued. There were some slight differences in terms of race on this question; Hispanic respondents were more likely than other groups to say that their input was always valued, while Somali parents were the least likely to say their input was always valued (Figure 11).

11. Felt respected and valued by doctors, by race of child (N=22)

In the past year, how often did your doctor help you feel respected or that your input was valued in your child's care?	Always	Usually	Sometimes	Never
African American	3	1	1	0
Hmong	2	2	2	0
Somali	1	4	0	0
Hispanic	5	0	1	0
Total	**11**	**7**	**4**	**0**

It should be noted that, while most parents in the parent interviews indicated that their doctor spent time with their family and communicated information, in an open-ended question several respondents said they feel rushed through their appointments, or sometimes struggle to understand everything their doctor says, even with an interpreter.

> *I do feel comfortable asking questions, but often they do not give me the time to do it. – Parent of CYSHN*
>
> *Yes, my child's doctor explains the services well; however, sometimes the doctor might be rushing to other patients and I don't get the time I need to get all my questions answered. Typically he refers me back to the nurse for resources. – Parent of CYSHN*
>
> *The fact that I am a Spanish speaker sometimes makes it hard to communicate or understand even with the use of interpreter. – Parent of CYSHN*

Many providers are respectful of customs and beliefs, but more work is needed

Many parents felt that their health care providers were sensitive to their cultural values. In the Gaps Analysis survey, 61 percent of parents said their health care providers are always or almost always sensitive to their family's values and customs; 34 percent felt this was sometimes the case. And nearly two-thirds of respondents felt that medical help was provided in a way that fit with their family's values (Figure 12).

12. Values and customs (N=95)

How often…	Always or almost always	Sometimes	Rarely	Never	Don't know
are doctors and other health care providers sensitive to your family's values and customs?	61%	34%	5%	0%	0%
is help provided in a way that fits with your values and customs?	66%	23%	2%	0%	9%

Over half of respondents in the Gaps Analysis survey felt that providers have a good understanding of their cultural and ethnic background, while more than one-quarter felt that they have a good understanding, but it could be improved (Figure 13).

13. Understanding cultural background by providers and agencies (N=95)

	N	%
Good understanding	54	57%
Some understanding, but could be better	27	28%
No understanding	7	7%
Don't know	7	7%

However, in the parent interviews, which focused specifically on families from diverse cultural communities, equal numbers of parents said they had been discriminated against because of their culture or beliefs (36% each; Figure 14). Several parents had also noticed that their families were treated differently at appointments (e.g., longer wait times), but were unsure if they wanted to label this different treatment as discrimination. Some parents also noted that, while they had not experienced discrimination from their health care provider, they had experienced discrimination from clinic support staff, such as a receptionist.

14. Discrimination because of culture [open-ended] (N=22)

Do you feel you have been discriminated against because of your culture or that your beliefs were not respected?	N	%
No	8	36%
Yes	8	36%
Not from my doctor, but yes from the receptionist/support staff	3	14%
Unsure	3	14%

Mixed feelings about care coordination

Over half of respondents (58%) in the Gaps Analysis survey had received services from a case manager, care coordinator, or social worker in the past 12 months. This percentage was smaller among the parents interviewed by PACER Center staff—43% said that they had someone who coordinates their child's care.

Both groups of respondents were asked about the helpfulness of their care coordination. Gaps Analysis respondents had mixed opinions, with one-third saying that it was very helpful, and a similar number of respondents saying it was not helpful (Figure 15). When asked how care coordinators could be more helpful, the most common response was that they should be more knowledgeable about the resources available to families (42%). Other respondents felt that care coordinators should be in more frequent contact with families (22%) and provide more services and resources (17%).

15. Helpfulness of case manager, care coordinator, or social worker (N=55)

	N	%
Very helpful	18	33%
Somewhat helpful	22	40%
Not helpful	15	27%

On the other hand, parents in the parent interviews tended to have more positive feedback; 88 percent said their care coordinator was very helpful, although this is out of a total of eight respondents (Figure 16). When asked if they had any suggestions for improving care coordination services, parents interviewed by PACER Center staff most often suggested providing a list of available community or clinic resources (five respondents).

16. Helpfulness of care coordination (N=8)

How helpful has the Care Coordinator been in coordinating your child's care among health care providers, specialists, or community organizations and staying informed about services your child is receiving?	N	%
Very helpful	7	88%
Somewhat helpful	1	13%
Not very helpful	0	0%
Not at all helpful	0	0%

Note: *One respondent skipped this question.*

Appendix

Preliminary research questions

Additional data tables: Stakeholder workgroup web survey

Additional data tables: Parent workgroup web survey

Additional data tables: Gaps analysis

Additional data tables: Parent interviews

Preliminary research questions

The following questions should be considered preliminary. In the coming period, we will discuss all of these questions in greater depth and modify them as appropriate; particularly the questions below, which relate to the overall project, rather than one specific goal area:

- To what extent do parents report feeling more supported and empowered in parenting their CYSHN?
- What is the level of satisfaction, as well as frustration with the system, among families and other stakeholders (e.g. social workers, school staff, clinic staff, etc.)?

Goal 1: Increase stakeholder engagement and partnerships within statewide initiatives.	**Goal 2:** Increase cross-systems integration through providing more effective care coordination services for CYSHN and their families.	**Goal 3:** Increase the knowledge of services and supports available for CYSHN through the enhancement of a "CYSHN Navigator" (shared resource) for providers and families of CYSHN.
Process questions		
■ Who is involved in the Stakeholder Workgroup? ■ Who is involved in the Parent Workgroup? – How often do they participate? – What activities are they engaged in? – How engaged were they? – How satisfied were they? Which partner initiatives have CYSHN representation?	**Care Coordination Collaboratives:** ■ Who is involved in CYSHN Care Coordination Collaboratives? – What are the characteristics of participants and speakers? – How often do they participate? How many meetings were there? – What activities are they engaged in? – Are the participants on the care coordination collaboratives representative of the care coordinators that families have? **Care Coordination Toolkit:** ■ How many care coordinators have received the web-based toolkit? Used the toolkit? Been trained on the toolkit? ■ How many families have been trained on the toolkit? **Family / Youth Educational Materials:** ■ How many families have received the educational materials/trainings? ■ How many youth have received the educational materials/trainings? ■ To what extent are parents and youth satisfied with the materials that have been developed for them? Do families and other stakeholders understand the terminology (e.g. medical home and care coordination)?	■ What is the shared resource? – How was it developed? – Who was involved in its development? Who operates/ maintains it? – How many people have access to the shared resource? How many people are using it? What are their characteristics? – How do people access the shared resource? ■ Are parents and providers of CYSHN satisfied with the shared resource?

Outcome questions

- To what extent has stakeholder knowledge about the systems in place for CYSHN improved?
- To what extent has communication improved, or become more coordinated, between stakeholders?
- To what extent do new statewide health care initiatives plan around the needs of CYSHN and their families?
- To what extent are Parent Workgroup members satisfied with their participation in the decision-making process?
- To what extent is the Stakeholder Task Force a sustainable group that can continue to focus on the needs of CYSHN after the grant is complete?

OVERALL OUTCOME INDICATOR
(gathered via national survey)

- To what extent are families seen as partners in shared decision-making?
- How satisfied are families with the services they receive?

Goal: Increase number of CYSHN whose families are partners in shared decision-making at all levels and are satisfied with the services they receive by 10% over 2009/2010 NS-CSHCN level.

- Are the various types of coordinators knowledgeable about each other and their different roles?
- Are care coordinators working together with each other better?
- To what extent are families more knowledgeable about the health care home/medical home model?
- Are families more knowledgeable about what care coordination is, who their care coordinators are, and what their roles include?
- To what extent are services and supports easier to use or access for families?
- To what extent are families satisfied with the amount of care coordination they receive?

OVERALL OUTCOME INDICATOR
(gathered via national survey)

- To what extent are families receiving integrated care through a family-centered medical home/health care home?
- Are families of CYSHN receiving effective care coordination?

Goal: Increase number of CYSHN whose families report receiving integrated care through a patient/family-centered medical home/health care home by 20% over the 2009/2010 NS-CSHCN level. Increase the number of CYSHN whose families report receiving effective care coordination by 20% over the 2009/2010 NS-CSHCN level.

- To what extent are families of CYSHN more knowledgeable about the services available to them?
- To what extent do parents understand how to navigate the system for their CYSHN?
  - – Are families more comfortable navigating the system?
- Is there increased use in the services and supports that are currently available?

OVERALL OUTCOME INDICATOR
(gathered via national survey)

- How easily are families able to access community-based services?

Goal: Increase number of CYSHN whose families report being able to easily access community-based services by 20% over 2009/2010 NS-CSHCN level.

Additional data tables: Stakeholder workgroup web survey

A1. Role in the Stakeholder Workgroup (N=16)

	N	%
Medical professional (e.g., doctors, nurses, care coordinators)	6	38%
Parents	6	38%
Other	4	25%

A2. Expectations of what Stakeholder Workgroup should accomplish (N=14)

	N	%
Problem solving/Implement change	7	50%
Provide advice/Make recommendations	5	36%
Meet the goals of the grant	2	14%

A3. Knowledge about the grant and Workgroup (N=16)

	I'd like to learn <u>a lot</u> more	I'd like to learn <u>a little</u> more	I know enough
The overall goals of the Systems Integration Grant	25%	44%	31%
The purpose of the Stakeholder Workgroup	13%	56%	31%
Your specific role in the Stakeholder Workgroup	13%	56%	31%
The definitions of terms, such as health care homes and medical homes	13%	13%	75%
The history and legislation around medical homes	6%	19%	75%
Other*	0%	13%	0%

Note: *Other includes: "I understand the high level goals. It would be nice to clarify what the intended outcomes are" and "How the group can contribute with three meetings"*

A4. Primary challenges for the Systems Integration Grant (N=12)

	N	%
Time, money and/or red tape	5	42%
Implementing recommendations, taking action	3	25%
Coordination across other strategic initiatives (e.g., definitions, outcome tracking, rules/laws)	3	25%
Unsure/Lack of knowledge about grant	3	25%
Systems change is difficult	2	17%

Note: *Percentages add up to more than 100, because stakeholders were able to give more than one reason.*

A5. Defining success for the Systems Integration Grant (N=12)

	N	%
Families have new/different services available	5	42%
More coordinated systems of care	4	33%
Strategies are implemented	2	17%
Grant goals are met	2	17%
Other	3	25%

Note: *Percentages add up to more than 100, because stakeholders were able to give more than one reason. "Other" responses include: "Add sessions to communicate about the SIG," I'm still looking into this," and "I don't recall the basics of the grant, so it's hard to respond."*

Additional data tables: Parent workgroup web survey

A6. Factors related to parent leadership (N=5)

Currently, how would you rate your…	**Excellent**	**Good**	**Okay**
Energy and enthusiasm to lead?	5	0	0
Involvement in planning the care your child gets outside of your home (e.g. in the school or in the community)?	4	1	0
Ability as a parent leader to make an impact on the issues related to CYSHN that are important to you?	3	2	0
Ability to find resources to help make things better for your family or families like yours?	3	1	1
Confidence as a parent leader?	2	3	0

Note: *Respondents were asked to rate their responses on the following scale: Excellent, Good, Okay, Poor, or Very Poor. No respondents provided a Poor or Very Poor rating for any item; therefore those columns are excluded from the table above.*

A7. Ability to lead (N=5)

Currently, how would you rate your…	Excellent	Good	Okay
Ability to lead efforts to make the system better for CYSHN?	2	2	1

Note: *Respondents were asked to rate their responses on the following scale: Excellent, Good, Okay, Poor, or Very Poor. No respondents provided a Poor or Very Poor rating for any item; therefore those columns are excluded from the table above.*

What factors have enabled you to have an impact as a parent leader? (N=3)
[I am] tenacious, [I do] research, and [I am] a good listener.
I have experience in and outside of the system and have learned a lot.
Real life experiences; being able to understand where others are coming from; and being able to articulate the feelings I have to others
What challenges have you experienced that have prevented you from being the parent leader you aspire to be? (N=2)
Training opportunities are hard to find and many are costly. It is often difficult to find paid opportunities to participate.
I don't have enough time. I need to work full time and advocate for my child…I would LOVE to find a way to be paid enough to advocate for the changes that are needed so that I would not have to have another job. I often don't have enough time to research all the information I need to be able to defend my position for change. I don't want to look like the crazy parent who just wants things for my child. I want to make an informed and valid argument about what type of change needs to happen and why is important to all the parties involved, not just me.

A8. Community connections (N=5)

Currently, how well do…	Very well	Somewhat well	Not very well
You reach out to other parents in your community to help you change things?	4	1	0
Other parents in your area contribute to efforts to make things better for children with special needs?	1	3	1

Note: *Respondents were asked to rate their responses on the following scale: Very well, Somewhat well, Not very well, Not at all well. No respondents provided a Not at all well rating for any item; therefore that column is excluded from the table above.*

A9. Level of involvement (N=5)

In the past year, [I have]…	N
Attended meetings or events in the community to improve services or programming to meet my child's needs	**5**
How often did you feel your input was acknowledged?	
Always	1
Usually	2
Sometimes	2
Never	0
Written letters, made phone calls, or talked in person to policy makers to make the system better for my child or family?	
How often did you feel your input was acknowledged?	**5**
Always	1
Usually	1
Sometimes	3
Never	0
Attended meetings at my child's school to improve services for my child	**3**
How often did you feel your input was acknowledged?	
Always	1
Usually	0
Sometimes	2
Never	0

Note: *Respondents were asked to rate their responses on the following scale: Very well, Somewhat well, Not very well, Not at all well. No respondents provided a Not at all well rating for any item; therefore that column is excluded from the table above.*

A10. Difficulty getting involved (N=5)

	Yes	No
In the past year, did you want to get involved in advocating for children and youth with special health needs (CYSHN) and their families, but did not know how to get involved?	0	5

A11. Organizations that respondents are currently involved in (N=5)

What organizations (in your community, state-wide, or nationally) are you involved in to advocate for children and youth with special health needs (CYSHN) and their families?
MDH CYSHN Parent Work Group (5 respondents)
Family Voices of Minnesota (3 respondents)
Child and Adolescent Behavioral Health Services (CABHS) (1 respondent)
Essentia Health Family Advisory Committee (1 respondent)
Help Me Grow Workgroup (1 respondent)
MDH MCH Advisory task force (1 respondent)
MDH Needs Assessment Leadership Team (1 respondent)
Medical Home Committee at local hospital (1 respondent)
Minnesota Association for Children's Mental Health (MACMH) (1 respondent)
Minnesota Organization on Fetal Alcohol Syndrome (MOFAS) (1 respondent)
Northern Lights Special Ed Coop Interagency Council (1 respondent)
Parent-to-Parent (1 respondent)
Partners in Policymaking (1 respondent)

Note: *Responses add up to more than 100 percent, as respondents were able to list more than one organization.*

A12. Organizations that respondents want to be involved in (N=4)

Currently, what organizations or activities related to children and youth with special health needs would you like to be more involved with or have more information about?
Governor's Council on Disabilities; AMCHP; all of them!!!!
I would like to know more about ARC, UCP, and similar organizations that lobby policymakers. I don't want to just pay membership dues. I want to participate in making change.
I'm not sure. I'd like to know what my choices might be.
It is critical that policy change happen and we need to educate our legislators. I'd be interested in doing more testimony at hearings.

A13. Age of child with most complex health care needs (N=5)

	N
Under 18 years old	3
18 or older	2

A14. Health care for child with most complex health care needs (N=5)

	Yes	No	I don't know this about my adult child's care
Does your child have a care provider, such as a doctor or nurse, who knows your child and his/her history?	5	0	0
Do you have a place you usually go for routine care for your child to stay healthy (like for well child visits, for immunizations, or health physicals)?	4	0	1
Are there things your clinic or doctor has done to help prepare your child to manage his/her own health care?	3	2	0
Do you have a place you usually go when your child is sick?	3	1	1
Do you have any problems obtaining referrals when specialty care is needed for your child?	2	3	0

A15. Child's doctor (N=5)

In the past year, how often…	Always	Usually	Sometimes
Did your child's doctor and other health care providers make you feel respected or that your input was valued in your child's care?	4	1	0
Were your child's doctor and other health care providers sensitive to your family's culture or beliefs?	4	1	0
Did your child's doctor and other health care providers spend enough time with your child?	4	0	1
Did your child's doctor and other health care providers listen carefully to you?	3	2	0
Did your child's doctor and other health care providers provide you with the information that you needed?	2	2	1

Note: *Respondents were asked to rate their responses on the following scale: Always, Usually, Sometimes, Never, and Not applicable: I do not know this about my adult child's care. No respondents provided a Never or Not applicable rating for any item; therefore those columns are excluded from the table above.*

A16. Satisfaction with child's health care (N=5)

Overall, how satisfied are you with the health care your child receives?	N
Very satisfied	2
Somewhat satisfied	3
Somewhat dissatisfied	0
Very dissatisfied	0

A17. Ease of community-based services (N=5)

Are community-based services organized in ways that are easy for your child to use?	N
Always	0
Usually	1
Sometimes	1
Never	2

A18. Other parents in local area (N=5)

Are there parents in your local area who work with you regarding advocacy for children with special needs?	N
Yes	4
No	1

A19. Reasons for getting involved with the Parent Workgroup (N=5)

What made you decide to get involved in the Parent Workgroup (What do you hope to get out of it)?
When I was a single mother with a child with special health needs, I was in survival mode. I learned as I went along and have since found out that I am fighting the same fight that parents in my community were fighting when I was in school. I want this to change. It should not be this difficult! I am in a place where I have more support and am able to devote a little more time to advocate for system change rather than simply for my child's needs.
[I have] been through the process and hope to help others.
I believe that voices who are in outstate MN are often times not heard. I wanted to help be a voice that is heard.
I was asked by MOFAS to participate to bring the needs of those with an FASD to the table. I hope to learn how to improve education to providers at all levels to improve care.
I am dedicated to building a strong parent network for families of CYSHN and hope to bring more family voices to the table in design, planning, and evaluation of all programs and policies that affect CYSHN.

Additional data tables: Gaps analysis

A20. Services received in the past 12 months (N=98)

	N	%
Doctor/Primary care appointment	94	96%
Case management, care coordination, social worker	63	64%
Therapy (OT/PT)	62	63%
Medication management	53	54%
Mental health counseling, therapy, or psychiatry	49	50%
PCA	44	45%
Skills group and/or skills training	31	32%
Respite care	28	29%
Assistive technology, specialized equipment, and home modifications	27	28%
Caregiver support/training	24	25%
Transportation	22	24%
Day treatment for mental health	18	18%
Personal support/companion services	15	15%
Home health aide or visiting nurse	14	14%
Financial assistance	3	13%

Note: *Percentages add up to more than 100, because caregivers were able to indicate more than one service.*

A21. Type of help received in the past 12 months that was most helpful

Most helpful service is…	N	%
PCA (n=44)	26	59%
Doctor or primary care physician appointments (n=94)	11	12%
Therapy (OT/PT) (n=62)	12	19%
Medication management (n=53)	9	17%
Mental health counseling, therapy, or psychiatry (n=49)	9	18%
Respite care (n=28)	4	14%
Case management, care coordination, social worker (n=63)	1	2%
Skills group and/or skills training (n=31)	5	16%
Assistive technology, specialized equipment, and home modifications (n=27)	5	19%
Transportation (n=22)	1	5%
Personal support/companion services (n=15)	2	13%
Home health aide or visiting nurse (14)	1	7%
Financial assistance (3)	1	33%
Day treatment for mental health (n=18)	0	0%
Caregiver support/training (n=24)	0	0%

A22. Ease of getting most helpful service

Most helpful service is…	N	Very easy	Somewhat easy	Difficult
Assistive technology, specialized equipment, and home modifications	5	0%	40%	60%
PCA (Personal Care Assistant)	26	16%	36%	48%
Transportation	1	0%	100%	0%
Personal support/companion services	2	0%	0%	50%
Home health aide or visiting nurses	1	0%	0%	100%
Doctor or primary care physician appointments	11	64%	27%	9%
Therapy (OT/PT)	12	33%	50%	17%
Mental health counseling, therapy, or psychiatry	9	33%	22%	33%
Medication management	9	11%	33%	44%
Skills groups and/or skills training	5	20%	40%	40%
Case manager, care coordinator, or social worker	1	0%	100%	0%
Respite care	4	0%	0%	100%
Financial Assistance (incl utilities)	1	0%	100%	0%

A23. Factors that make most helpful service difficult to get

Most helpful service is…	N	Lack of providers: appointment schedule/ availability, location	Eligibility	Lack of qualified providers	Not enough services
Assistive technology, specialized equipment, and home modifications	5	0%	100%	33%	0%
PCA (Personal Care Assistant)	26	25%	33%	33%	25%
Transportation	1	0%	0%	0%	0%
Personal support/companion services	2	0%	0%	100%	0%
Home health aide or visiting nurses	1	100%	0%	0%	0%
Doctor or primary care physician appointments	11	0%	0%	0%	0%
Therapy (OT/PT)	12	67%	0%	0%	0%
Mental health counseling, therapy, or psychiatry	9	100%	50%	0%	25%
Medication management	9	0%	0%	0%	50%
Skills groups and/or skills training	5	50%	0%	25%	25%
Case manager, care coordinator, or social worker	1	0%	100%	33%	0%
Respite care	4	25%	33%	33%	25%
Financial Assistance (incl utilities)	1	0%	0%	0%	0%

Note: *Percentages add up to more than 100, because caregivers were able to indicate more than one service.*

A24. Quality rating of most helpful service

Most helpful service is…	N	Very good	Good	Not good
Assistive technology, specialized equipment, and home modifications	5	75%	25%	0%
PCA (Personal Care Assistant)	26	54%	38%	8%
Transportation	1	100%	0%	0%
Personal support/companion services	2	50%	0%	50%
Home health aide or visiting nurses	1	0%	100%	0%
Doctor or primary care physician appointments	11	73%	18%	9%
Therapy (OT/PT)	12	92%	8%	0%
Mental health counseling, therapy, or psychiatry	9	67%	33%	0%
Medication management	9	11%	78%	0%
Skills groups and/or skills training	5	80%	20%	0%
Case manager, care coordinator, or social worker	1	100%	0%	0%
Respite care	4	25%	75%	0%
Financial Assistance (incl utilities)	1	0%	100%	0%

A25. Is there help you are unable to get, but think you need? (N=94)

	N	%
Yes	49	52%
No	35	37%
Don’t know	10	11%

A26. Reasons for not receiving needed service (N=49)

	N	%
It is not available near me	11	22%
It is too hard to get it (lack of time, confusing process)	11	22%
I cannot afford it (high copays; no sliding fee)	10	20%
There is a long waiting list for it	6	12%
I am not eligible for it	6	12%
The people who provide the help do not understand my culture, beliefs, or preferences	3	6%
The hours are not convenient	2	4%
I do not feel comfortable using it	1	2%
Other	25	51%
Don't know	1	2%

Note: *Percentages add up to more than 100, because caregivers were able to indicate more than one reason.*

A27. Doctors spent enough time with child (N=95)

How often do doctors and other health care providers of your child(ren) with special health care needs spend enough time with your family during appointments?	N	%
Always or almost always	58	61%
Sometimes	30	32%
Rarely	5	5%
Never	2	2%

A28. Have a place to get advice about child's health (N=94)

Is there a place your child(ren) with special health needs goes when he/she is sick and you need advice about his/her health?	N	%
Yes	83	88%
No	9	10%
Don't know	2	2%

A29. Location of place to get advice about child's health (N=83)

	N	%
Doctor's office or clinic	77	93%
Urgent care	3	4%
Hospital Emergency Room	1	1%
Other health center	2	2%

A30. Have a place to get routine preventative care (N=93)

	N	%
Yes	90	97%
No	2	2%
Don't know	0	0%

A31. Helpfulness of case manager, care coordinator, or social worker (N=55)

	N	%
Very helpful	18	33%
Somewhat helpful	22	40%
Not helpful	15	27%

A32. Ways for case manager, care coordinator, or social worker to be more helpful (N=36)

	N	%
Know resources available	15	42%
More frequent contact	8	22%
Provide more services/resources	6	17%
Listen to client needs	5	14%
Know clients and needs	5	14%
Hire knowledgeable staff	3	8%
Return phone call	3	8%
Decrease caseload	2	6%

Additional data tables: Parent interviews

A33. Age of child with most complex special health needs (N=22)

	N	%
0 to 6 years old	5	23%
7 to 9 years old	7	32%
11 to 14 years old	6	27%
15+ years old	4	18%
Minimum age: **3 years old**		
Maximum age: **17 years old**		
Average age: **10 years old**		

Note: *Some respondents have more than one child with special health care needs; however, parents were asked to answer questions for their child with the most complex special health care needs.*

A34. Routine care for child with special health needs

% saying "yes"	N	%
Do you have a place you usually go for routine care for your child to stay healthy? (N=22)	21	95%
Is there someone at this place who knows your child's history? (N=18)*	16	89%

** Four respondents skipped this question.*

A35. Place you go when child is sick (N=22)

Where do you usually go when this child is sick? Is it most often…	N	%
A clinic or doctor's office	19	86%
Emergency room	2	9%
Urgent care	1	5%
Other health care center	0	0%

A36. Doctors spent enough time with child (N=22)

In the past year, how often did your child's doctor and other health care providers spend enough time with your child?	N	%
Always	9	41%
Usually	6	27%
Sometimes	7	32%
Never	0	0%

A37. Doctors spent enough time with child, <u>by race of child</u> (N=22)

	Always	Usually	Sometimes	Never
African American	3	1	1	0
Hmong	2	2	2	0
Somali	1	2	2	0
Hispanic	3	1	2	0

A38. Felt respected and valued by doctors (N=22)

In the past year, how often did your doctor help you feel respected or that your input was valued in your child's care?	N	%
Always	11	50%
Usually	7	32%
Sometimes	4	18%
Never	0	0%

A39. Felt respected and valued by doctors, <u>by race of child</u> (N=22)

	Always	Usually	Sometimes	Never
African American	3	1	1	0
Hmong	2	2	2	0
Somali	1	4	0	0
Hispanic	5	0	1	0

A40. Doctors provided needed information (N=22)

In the past year, how often did your doctor provide you with the information that you needed?	N	%
Always	11	50%
Usually	5	23%
Sometimes	6	27%
Never	0	0%

A41. Doctors provided needed information, by race of child (N=22)

	Always	Usually	Sometimes	Never
African American	3	1	1	0
Hmong	2	2	2	0
Somali	3	1	1	0
Hispanic	3	1	2	0

A42. Doctors listened carefully (N=22)

In the past year, how often did your child's doctors and other health care providers listen carefully to you?	N	%
Always	8	36%
Usually	8	36%
Sometimes	6	27%
Never	0	0%

A43. Doctors listened carefully, by race of child (N=22)

	Always	Usually	Sometimes	Never
African American	3	0	2	0
Hmong	1	3	2	0
Somali	1	3	1	0
Hispanic	3	2	1	0

A44. Doctors' ability to communicate [open-ended] (N=22)

% saying "yes"	**N**	**%**
Does your doctor explain the service that will be provided to your child and why?	20	91%
Do you feel that you get all of your questions answered?	21	95%
Do you feel comfortable asking questions with the doctor?	21	95%
Do they explain things to you that you can understand them?	21	95%

A45. Discrimination because of culture [open-ended] (N=22)

Do you feel you have been discriminated against because of your culture or that your beliefs were not respected?	**N**	**%**
No	8	36%
Yes	8	36%
Not from my doctor, but yes from the receptionist/support staff	3	14%
Unsure	3	14%

A46. Helpfulness of doctors at meeting needs (N=22)

Overall, how much do you feel that your health care providers meet your child's and family's needs?	**N**	**%**
Very helpful	11	50%
Somewhat helpful	10	45%
Not very helpful	1	5%
Not at all helpful	0	0%

A47. Concerns about child's overall health (N=21)

During the past 12 months, did you have any issues or concerns about your child's growth, development, learning, behavior, or mental health that you asked about during a visit to the doctor or health provider?	**N**	**%**
Yes	16	76%
No	5	24%

Note: *One respondent skipped this question.*

A48. Doctors' helpfulness at answering questions [open-ended] (N=16)

How helpful was the doctor or other health care provider in answering your questions? Did the doctor or health care provider do any follow-up?	N	%
The doctor or other provider was helpful and/or provided follow-up	13	81%
Less than helpful and/or did not provide follow-up	3	19%

A49. Reference to a specialist (N=22)

	N	%
Yes	16	76%
No	6	24%

A50. Doctors' follow-up regarding specialist [open-ended] (N=16)

Did your child's doctor or other health providers follow-up with you to ask if your child visited the specialist or ask about the visit?	N	%
Yes	8	50%
No	6	38%
No response	2	13%

A51. Reference for other services (N=22)

During the past 12 months, did your child's doctor or clinic refer your child for any other services in the community such as follow-along program, Home visiting, Head Start, ECFE, special ed, public Health, or other community service?	N	%
Yes	9	41%
No	13	59%

A52. More services needed [open-ended] (N=13)

Are there services in the community that you feel that the doctor or health providers could have connected you to?	N	%
Yes	3	23%
No	3	23%
Don't know	1	8%
No response	6	46%

A53. Child's care coordination (N=21)

Is there someone who coordinates your child's care among different doctors, specialists, or services that your child needs and gathers the information about your child from these sources to plan their care?	**N**	**%**
Yes	9	43%
No	12	57%

Note: *One respondent skipped this question.*

A54. Helpfulness of care coordination (N=8)

How helpful has the Care Coordinator been in coordinating your child's care among health care providers, specialists, or community organizations and staying informed about services your child is receiving?	**N**	**%**
Very helpful	7	88%
Somewhat helpful	1	13%
Not very helpful	0	0%
Not at all helpful	0	0%

Note: *One respondent skipped this question.*

A55. Description of care coordination (N=8)

Can you describe what they do to coordinate your child's care? Can you say more about how care coordination has or has not helped you or your family?
Gathers info, sets appointments, follow-ups, provides answers to any questions or concerns I may have and has learned my family.
Everything I need as far as appointments gathered information coordinating the process. When they know my child needs a specialist this information is given to the coordinator who clarifies with the doctor the why and what information is needed. The coordinator then aligns everything up including my availability.
Asking questions and what do I need and what can be done and how they are effective.
Helpful in working with my schedule, call back, follow through with connections and follows up with coordinating my appointment.
The care coordinator only worked on the transfer to the other facility for OT, PT, and such, but was not helpful with other community resources. I wish there was a care coordinator that would be present at the beginning of the hospital stay or be available at the clinic so that we can access community health care resources.
It's very effective when it is done properly.
They help me coordinate phone calls and communications between Doctors.
He gets me the appointments, transportations etc.

Note: *One respondent skipped this question.*

A56. Other suggestions [open-ended] (N=21)

Do you have any suggestions for ways in which your clinic could be more helpful in coordinating with other services?	N	%
None	8	38%
I would like a list of available community or clinical resources	5	24%
I wish I had a care coordinator	4	19%
Care coordinators do a good job/are helpful	3	14%
Need care coordinators who speak other languages	2	10%
Ask families about their individual health care needs	1	5%

Note: *One respondent skipped this question. Numbers add up to more than 100 percent as respondents were able to give more than one suggestion.*

A57. Child’s racial and ethnic background (N=22)

	N	%
African American	5	23%
American Indian	1	5%
Hispanic or Latino	6	27%
Hmong	5	23%
Somali	6	27%
White	1	5%
Other	1	5%

Note: *Responses add up to more than 100 percent, as respondents could select more than one race or ethnicity.*

A58. Primary language spoken at home (N=22)

	N	%
English	10	45%
Spanish	6	27%
Hmong	3	14%
Somali	3	14%