

ABCD III technical report: Parent interviews

Parent experiences across pilot sites in four counties

DECEMBER 2012

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Introduction

In 2009, Minnesota became one of five states chosen to participate in the Assuring Better Child Health and Development program (ABCD III), a program funded by The Commonwealth Fund and administered by the National Academy of State Health Policy (NASHP). Led by the Minnesota Department of Human Services (DHS), the state's ABCD III project was intended to develop and test sustainable models for improving care coordination and referral processes between pediatric primary care, other medical providers, and child and family service providers offering developmental and mental health services to children birth through age 5. The project supported four pilot sites (in Anoka, Olmsted, Ramsey, and Saint Louis Counties).

Wilder Research was contracted to evaluate the ABCD III project. A multi-method evaluation approach was developed to assess the impact of the project, which included interviews conducted with parents whose child received care from each participating clinic, key informant interviews with staff from each pilot site, and a review of screening and referral data captured by each clinic. The parent interviews were conducted to understand parent perceptions of the screening children received at the pilot clinics, how care was coordinated, parents' comfort with and follow-up on referrals, the usefulness and comprehensiveness of anticipatory guidance given, the comprehensiveness of their well-visits, and their satisfaction with the developmental and mental health aspects of the visit.

An initial set of parent interviews were conducted at baseline (2010-2011) and a second round of interviews took place again near the end of the project (2012) to assess changes in parent perceptions and experiences over time. This technical report provides the full results from the second round of interviews conducted with 125 parents of young children served at primary clinics involved with the ABCD III project. Results from the baseline interviews are also incorporated into this report as comparison data, but change over time should be interpreted with caution (see limitations section). Key findings from this technical report have been integrated into the final, comprehensive report for the project, also prepared by Wilder Research.

About the Help Me Grow program

Of particular interest to DHS is increasing linkages between primary care clinics and the Help Me Grow: Infant and Toddler Intervention or Preschool Special Education programs. Help Me Grow is an early intervention system administered by the Minnesota Department of Education to provide service coordination, Early Childhood Special Education and related services to eligible children birth through age 5 who may be experiencing delays in their development for several reasons, including special health conditions.

About the pilot teams

Pilot teams located in Anoka, Olmsted, Ramsey and Saint Louis counties were selected to participate in the ABCD III project. The name and unique characteristics of the clinics that participated in the project are briefly described below:

Anoka County: Fridley Children's and Teenagers' Medical Clinic and community partners – Fridley, Minnesota and North Metro Pediatrics and community partners – Coon Rapids, Minnesota. The school district partner on the project was Spring Lake Park. North Metro Pediatrics implemented changes in practice as a result of the pilot project, but did not refer any children to the Spring Lake Park school district.

Olmsted County: Mayo Pediatrics and community partners – Rochester, Minnesota.

Ramsey County: HealthPartners White Bear Lake Clinic and community partners – White Bear Lake, Minnesota. Health Partners joined the Ramsey County team in early 2011 after the East Side Family Clinic discontinued participation in ABCD III in late 2010.

Saint Louis County: Saint Luke's Pediatric Associates and community partners – Duluth, Minnesota. It should be noted that this clinic was involved with another initiative aimed at improving care coordination. The Medical Home Initiative for children with special health care needs (2005-2009) involved medical home teams of primary care providers, care coordinators, and parents in quality improvement activities.

Research methods

The parent survey interview tool was developed collaboratively with DHS staff in 2010. The tool was reviewed and slightly modified in 2012 to remove or modify questions that did not provide useful information at baseline. Two sampling methods with different eligibility criteria were used to capture information from a randomly selected group of patients reflecting the clinic's general patient population and a targeted group of patients who had been screened as eligible and/or referred to early intervention services.

Sample criteria

All families were selected because they had a child who received services from a pediatric primary care provider at one of the five participating clinics.

Sampling Method 1: Random selection of eligible families

The criteria used to identify a random sample of families that reflect the clinic's early childhood patient population follows the sampling criteria used at baseline. All

participating clinics were asked to submit a list of children age 5 or younger (or, for Olmsted County, age 3 or younger) who were screened in the last year and met the following additional criteria:

- Received care from a pediatric primary care provider
- Enrolled in Minnesota Health Care Plans
- Received well-child visit in the past 3 months
- Current caregiver contact information available

Wilder Research used this list to randomly select 50 families who were asked to participate in the telephone survey. If two children from the same family were included on the list, one child was randomly selected. In the cases where clinics did not have 50 eligible families, all identified families were selected.

Sampling Method 2: Targeted selection of families who have had children with elevated screening scores and/or have been referred to early intervention services/ Help Me Grow since the study began

All clinics use an Access database to track and report information for children birth through age 5 who are enrolled in Minnesota Health Care Plans and have elevated screening scores or are referred to early intervention services. To gather feedback from a sample of parents known to have a child identified with a potential developmental concern, Wilder Research contacted parents of children who met the following criteria:

- Had an elevated screening score, or
- Were referred to early intervention services/Help Me Grow (regardless of screening score)
- Are enrolled in Minnesota Health Care Plans
- Had current caregiver contact information available
- For Anoka County only: Are enrolled in the Spring Lake Park school district

For this method Wilder Research gave each clinic a list of eligible families identified from the clinic's Access database, and asked that they provide contact information. In cases in which more than one child per family was sampled, one child was randomly

Although Olmstead County/Mayo Pediatrics targeted screening process occurs at 18 months, they referred children from birth through 5 years. Thus, children from birth through age 5 are included in the targeted sample.

selected. North Metro Pediatrics, one of two clinics that were part of the Anoka County pilot team, did not serve any children who were enrolled in the Spring Lake Park School district during the course of the project. As a result, no patients from that clinic were eligible to be included in the target sample.

Selected families were sent a letter briefly explaining the study and the voluntary nature of their participation. Parents were given the option of contacting Wilder Research directly to decline to participate in the study.

Additional information about interviews conducted

Between July and September 2011, trained interviewers from Wilder Research conducted computer-assisted telephone interviews with parents from the participating clinics. Interviews were conducted in English and Spanish. Multiple attempts were made to contact families, and call-backs were arranged at convenient times. Parents who participated in the interview received a \$15 gift card to Target or Walmart to thank them for their time

Although parents in both the randomly selected group and the targeted group were asked the same set of interview questions, there was one exception. When asked to think back over a period of time, parents in the random sample were asked to think about the past 12 months (to match questions that were asked of the randomly selected group at baseline). However, parents in the targeted sample were asked to think about the past 18 months in order to match the timing of the ABCD III implementation activities at the clinic. A copy of the interview guide is included in the Appendix.

Limitations

The parent survey is one part of a larger set of data collection activities structured to understand the impact and effectiveness of the ABCD III project. This technical report is a summary of data collected through the parent interviews, but these findings should be considered in the context of other data gathered through the evaluation.

A series of limitations associated with the sampling methodology and sample size is briefly described below:

■ Given the small N—or total amount of responses for a given question—throughout the report, it is important to interpret these results with caution. While site-level data are presented in this technical report, the patients interviewed from each clinic comprise only a small percentage of the total pediatric population each clinic serves. Therefore, the results may not be representative of the full patient population.

- The baseline survey includes data from patients of one clinic that is no longer involved with the project. Eight families who were patients of the East Side Family Clinic were interviewed at baseline. However, this clinic ended its participation in the project in late 2010 and was replaced on the Ramsey County pilot team by the White Bear Lake Health Partners Clinic. Baseline data from the White Bear Lake clinic were collected from a sample of patients in 2011 and are included in the aggregate totals highlighted in this report.
- Different strategies were used for sampling age groups between baseline and follow-up (for the "random" sample, only). During baseline random sample selection, Wilder Research staff excluded from the sample those families whose eligibility was based on a child under 12 months old. This was because parents were asked to consider experiences over the past year, so families with very young children would not have the same frame of reference for service use as children over the age of 12 months. The follow-up sample was designed to gather feedback from families of all eligible children, birth through age 5.
- Because random samples of patients were drawn at both data collection points, different parents were likely interviewed at baseline and in 2012. In addition, as mentioned above, one of the key differences in the two groups is that parents interviewed in 2012 tended to have younger children than those interviewed at baseline (67% of parents interviewed in 2012 had children less than 2 years old, compared to 50% of parents interviewed at baseline). As a result, potential changes over time could be a result of differences between the parent groups interviewed at the two time periods or variations in screening protocols for different age groups and not a true indication of changes in patient experience over time.
- The response rate for both of the parent samples at follow-up was relatively low (53% for the random sample and 30% for the targeted sample) (Figures 1, 2). Wilder Research interviewers were unable to locate 75 respondents. In addition, 13 respondents refused the interview, 42 respondents were unavailable after 10-15 attempts to reach them, and 5 respondents had other barriers to participation, including language issues. At baseline, the response rate was similar 55 percent of families included in the sample completed an interview.

Throughout the report, follow-up survey results from both the random and targeted parent sample are provided. In addition, when data from the random follow-up sample are presented, aggregate baseline data are also included in the tables. However, because of the limitations described above, comparisons between groups at follow-up and changes over time for the randomly sampled groups should be interpreted with caution.

1. Response rate by clinic (Random sample)

	Sample size	Number interviewed	Response rate
Fridley Children's and Teenagers' Medical Clinic	50	28	56%
North Metro Pediatrics	15	7	47%
Mayo Pediatrics (Rochester)	42	16	38%
St. Luke's Pediatrics (Duluth)	14	10	71%
Health Partners White Bear Lake	50	30	60%
Total	171	91	53%

2. Response rate by clinic (Targeted sample)

	Sample size	Number interviewed	Response rate
Fridley Children's and Teenagers' Medical Clinic	28	8	29%
North Metro Pediatrics*	NA	NA	NA
Mayo Pediatrics (Rochester)	45	14	31%
St. Luke's Pediatrics (Duluth)	35	8	22%
Health Partners White Bear Lake	24	10	42%
Total	132	40	30%

^{*} A sample was not generated for this clinic because it did not serve children that were enrolled in the Spring Lake Park school district, one of the eligibility criterion used by this pilot site team.

Finally, although all children identified in the lists provided by the clinic were to have been screened, referred, or received a recent well-child visit, only half (53%) of the parents in the random sample and 70 percent of parents in the targeted sample reported completing a questionnaire about their child's development in the past year. It is not known whether that reflects inconsistent screening practice, inaccurate recall of appointments during the past year, a misunderstanding of the survey question, a lack of time spent reviewing screening results during an appointment, or some other factor.

Presentation of data tables

Throughout this report the N, or total amount of responses for a given question, shift depending on whether respondents chose not to answer a question or did not know the response to a question. Also of note, when an N is less than 10, a number, not a percent,

will appear in the data tables. In addition, in tables that describe the results of the 2012 interviews of parents in the randomly selected group are presented, we also include a column that presents the results of the randomly selected interviews conducted at baseline (2011). As mentioned previously, caution should be used when making direct comparisons between the two groups and limited comparisons are made in the descriptive text. Finally, the structure of the technical report aligns closely with the order of the questions asked in the parent survey.

Summary of demographic characteristics

A majority of parents interviewed in the random sample (71%) had a child birth through age 3. Many (30%) were parents of infants, birth through 11 months old. Fewer parents interviewed in the target sample (37%) had children birth through age 2 and only 3 percent were parents of infants.

Respondents' children in the random sample encompassed a variety of backgrounds, but the majority of children (79%) were white. Eighteen percent were African American, 6 percent were Asian, 1 percent were American Indian, and 2 percent were identified as "other." Twenty percent identified as Hispanic or Latino (can be of any race).

Most of the children in the targeted sample were also white (64%). However, compared to the random sample, the targeted sample included higher percentages of the other racial/ethnic groups (20% African American, 10% Asian, 3% American Indian, and 3% "other"; 10% identified as Hispanic/Latino).

English was the primary language spoken at home across both the random sample (78%) and the targeted sample (80%). In the random sample, 11 percent spoke Spanish, 3 percent spoke Somali, 2 percent spoke Vietnamese, and 6 percent identified other languages, including Arabic, Tigranian, and Russian. In the targeted sample, 13 percent spoke Spanish, 3 percent spoke Vietnamese, and 5 percent specified other languages, including Cambodian and Amheric.

These data tables and additional demographic information are included in the Appendix (Figures A1-A14).

Parent interview results

Respondents' background experiences with participating clinics

Respondents were asked a series of questions about their relationship to the participating clinic: whether it was the place their child usually received care, how long their child has been a patient, if they had a primary health provider at the clinic, and if their primary provider was the provider seen during their child's last visit.

Screening and assessment

Respondents' perceptions of developmental aspects of visits

Respondents were asked about the services their child received regarding developmental screening, assessment, noted concerns, and referrals for testing. They were also asked about their satisfaction with the way the provider handled these aspects of the visit.

Forty percent of parents in the random sample and 70 percent of parents in the targeted sample reported that their child received some type of behavioral or mental health screening, assessment, or referrals in the past year (Figures 3-4). The use of screening tools varied widely by clinic for the random sample (37-81%).

Seventy-six percent of parents in the random sample reported that their child received some type of developmental screening, assessment, or referral by their health provider in the past year (Figure 3).

When asked about a variety of ways their child's development may have been assessed during a recent appointment, parents were most likely to say that their provider tested their child's learning and development (60%) or asked them to fill out a questionnaire about their child's development (53%) (Figure 3).

3. In the past 12 months, did your child's doctor or other health providers do any of the following to address learning or development? (Random sample)

	Percent YES						
	Fridley	North Metro	Mayo	Duluth	White Bear Lake	Total	Baseline total
	(N=27-28)	(N=7)	(N=16)	(N=10)	(N=28-30)	(N=88-91)	(N=122-125)
Note a concern about your child's learning or development that should be watched carefully?	26%	3	19%	-	27%	23%	17%
Test your child's learning or development?	56%	5	63%	40%	68%	60%	57%
Refer your child for testing of his/her learning or development?	15%	2	13%	-	10%	12%	10%
Refer your child for speech- language or hearing testing?	18%	2	19%	10%	14%	17%	13%
Have you filled out a questionnaire about specific concerns or observations you may have about your child's physical abilities or ability to communicate?	37%	6	81%	70%	40%	53%	58%
At least one of the above	71%	7	88%	70%	70%	76%	85%

Ninety-three percent of parents in the targeted sample reported that their child received some type of developmental screening, assessment, or referral by their health provider in the past year (Figure 4).

Parents were most likely to say that their provider had them complete a questionnaire about specific physical or communication concerns (70%) (Figure 4).

4. In the past 18 months, did your child's doctor or other health providers do any of the following to address learning or development? (Targeted sample)*

Percent YES

	Fridley	Mayo	Duluth	White Bear Lake	Total
	(N=8)	(N=14)	(N=8)	(N=10)	(N=40)
Note a concern about your child's learning or development that should be watched carefully?	5	43%	5	4%	50%
Test your child's learning or development?	4	57%	5	70%	60%
Refer your child for testing of his/her learning or development?	4	57%	4	50%	53%
Refer your child for speech-language or hearing testing?	5	57%	3	40%	50%
Have you fill out a questionnaire about specific concerns or observations you may have about your child's physical abilities or ability to communicate?	3	79%	7	70%	70%
At least one of the above	7	93%	8	90%	93%

Note: Percentages are not reported for clinics with fewer than 10 respondents.

Of those who received advice or next steps about aspects related to their child's learning and development (N=69 for random sample and N=30 for targeted sample), most parents (71% of the random sample, 81% of the targeted sample) received some advice or plans for next steps from their provider (Figures 5-6). In addition, most parents from the random (81%) and targeted (71%) samples were comfortable with the information from their child's doctor or other health providers (not reported).

^{*}As mentioned previously in the methods section, the look back period for parents in the targeted sample was 18 months rather than 12 months. This was done to match the timing of ABCD III implementation activities. The look back period for parents in the random sample was 12 months to match the way questions were asked of the random sample at baseline.

5. Other perceptions of parents whose child received some learning or development screening, assessment of referrals for testing? (Random sample)

	Fridley	North Metro	Mayo	Duluth	White Bear Lake	Total	2011 Baseline Total
	(N=20)	(N=7)	(N=14)	(N=7)	(N=21)	(N=69)	(N=106)
Received advice or plans for next steps from clinic doctor or staff	70%	5	79%	5	67%	71%	65%
"Very satisfied" with the way child's doctor or health providers handled this part of visit	85%	6	71%	6	86%	83%	80%

Note: Questions were asked only of those who received some type of screening or assessment in this area. Percentages are not reported for clinics with fewer than 10 respondents.

6. Other perceptions of parents whose child received some learning or development screening, assessment of referrals for testing? (Targeted sample)

	Fridley (N=7)	Mayo (N=13)	Duluth (N=8)	White Bear Lake (N=9)	Total (N=37)
Received advice or plans for next steps for clinic doctor or staff	5	92%	7	6	81%
"Very satisfied" with the way child's doctor handled his part of visit	4	39%	6	9	65%

Questions were asked only of those who received some type of screening or assessment in this area. Percentages are not reported for Note: clinics with fewer than 10 respondents.

Respondents' perceptions of behavior or mental health aspects of visit

Respondents were asked about the services their child received regarding behavioral or mental health screening, assessment, noted concerns, and referrals for testing.

Forty-six percent of parents in the random sample and 61 percent of parents in the targeted sample reported that their child received some type of behavioral or mental health screening, assessment, or referrals in the past year (Figures 7-8). There was wide variation in the rate of mental-health related screening, assessment, and referral among the clinics.

Percent YES

Overall, fewer respondents from the random sample reported that the health provider or doctor tested their child's behavior or mental health (38%) versus those who were tested for learning or development (60%) (Figures 3 and 7).

Similarly, parents included in the targeted sample were also less likely to report that they had completed a questionnaire about their concerns or observations regarding their child's behavior (18%) versus those who had completed a questionnaire regarding their child's development (70%) (Figures 4 and 8).

7. In the past 12 months, did your child's doctor or other health providers do any of the following to address behavior or mental health? (Random Sample)

	Fridley	North Metro	Mayo	Duluth	White Bear Lake	Total	2011 Baseline Total
	(N=26-28)	(N=7)	(N=16)	(N=9-10)	(N=29-30)	(N=89-90)	(N=122-125)
Note a concern about your child's behavior or mental health that should be watched carefully?	14%	1	6%	-	3%	8%	7%
Test your child's behavior or mental health?	22%	3	19%	-	17%	19%	21%
Have you fill out a questionnaire about specific concerns or observations you may have about how your child interacts with others or your child's behavior?	19%	5	56%	60%	30%	38%	52%
Refer your child for testing of his/her behavior or mental health?	-	1	-	-	-	1%	5%
At least one of the above	36%	86%	56%	60%	37%	46%	62%

8. In the past 18 months, did your child's doctor or other health providers do any of the following to address behavior or mental health? (Targeted Sample)

				White	Total
	Fridley	Mayo	Duluth	Bear Lake	(N=39-
	(N=7-8)	(N=14)	(N=8)	(N=10)	` 40)
Note a concern about your child's behavior or mental health that					
should be watched carefully?	2	29%	-	20%	20%
Test your child's behavior or mental health?	1	43%	3	50%	38%
Have you fill out a questionnaire about specific concerns or observations you may have about how your child interacts with					
others or your child's behavior?	1	29%	-	20%	18%
Refer your child for testing of his/her behavior or mental health?	2	57%	5	50%	51%
At least one of the above	38%	71%	63%	70%	63%

Note: Percentages are not reported for clinics with fewer than 10 respondents.

Of those who received advice or next steps about their child's behavior or mental health assessments (N=21 for random sample and N=13 for targeted sample), satisfaction ratings with the way the doctor or primary care provider handled behavioral or mental health assessments are high across both the random (71%) and targeted (63%) samples. However, only half of the parents whose child was screened or referred for mental health concerns (50% of parents in the random sample and 52% of parents in the targeted sample) reported that they received advice for next steps from their provider. All parents interviewed at both time periods were comfortable with the information they received from their child's health provider.

9. Other perceptions of parents whose child received some type of mental health screening, assessment, or referrals for testing (Random sample)

	Fridley (N=10)	North Metro (N=5-6)	Mayo (N=9)	Duluth (N=6)	White Bear Lake (N=11)	Total (N=41-42)*	2011 Baseline Total (N=48)
Received advice or plans for next steps from clinic doctor or staff	50%	3	6	2	46%	51%	56%
"Very satisfied" with the way child's doctor or health providers handled this part of visit	90%	4	7	5	73%	79%	73%

Note: Questions were asked only of those who received some type of screening or assessment in this area. Percentages are not reported for clinics with fewer than 10 respondents.

10. Other perceptions of parents whose child received some type of mental health screening, assessment, or referrals for testing (Targeted sample)

				White	
	Fridley	Mayo	Duluth	Bear Lake	Total
	(N=3)	(N=9-10)	(N=5)	(N=7)	(N=24-25)
Received advice or plans for next steps for clinic doctor or staff	1	40%	2	6	52%
"Very satisfied" with the way child's doctor handled this part of					
visit	2	4	2	7	63%

Note: Questions were asked only of those who received some type of screening or assessment in this area. Percentages are not reported for clinics with fewer than 10 respondents.

Variations in screening, assessment, and noted concerns, by age

There was variation in the rate of some screening and assessment activities, by age grouping in the random sample. Parents of older children, age 3 to 5, more frequently reported that they were asked to complete questionnaires regarding their child's physical abilities or ability to communicate (64%, compared to 51% of parents who had children under age 3) (Figure 11). However, these parents were less likely to report that they were asked to complete questionnaires regarding how their child interacts with others or their behavior (29%, compared to 40% of parents who had children under age 3).

11. Screening, assessment, noted concerns, by age (Random sample)

	Under age 3	Age 3-5	Total	2011 Baseline Total
Did the doctor or other health provider:	(N=71-74)	(N=17)	(N=88-91)	(N=125)
Note a concern about your child's <u>learning or development</u> that should be watched carefully?	22%	29%	23%	17%
Test your child's learning or development?	59%	65%	60%	55%
Have you fill out a questionnaire about specific concerns or observations regarding your child's physical abilities or ability to communicate ?	51%	64%	53%	58%
Note a concern about child's <u>behavior or mental health</u> that should be watched carefully?	8%	6%	8%	7%
Test your child's behavior or mental health?	19%	18%	19%	21%
Have you fill out a questionnaire about specific concerns or observations regarding how your child interacts with others or your child's behavior?	40%	29%	38%	51%

Among the targeted sample, parents of older children (age 3-5) were more likely to report that they were asked to completed questionnaires regarding both their child's development and mental health than parents of younger children (Figure 12).

12. Screening, assessment, noted concerns, by age (Targeted sample)

	Under age 3	Age 3-5	Total
Did the doctor or other health provider:	(N=14)	(N=25-26)	(N=39-40)
Note a concern about your child's <u>learning or</u> <u>development</u> that should be watched carefully?	64%	42%	50%
Test your child's learning or development?	57%	62%	60%
Have you fill out a questionnaire about specific concerns or observations regarding your child's physical abilities or ability to communicate?	64%	73%	70%
Note a concern about child's <u>behavior or mental</u> <u>health</u> that should be watched carefully?	21%	19%	20%
Test your child's behavior or mental health?	36%	39%	38%
Have you fill out a questionnaire about specific concerns or observations regarding how your child interacts with others or your child's behavior?	43%	56%	51%

Other developmental or mental health concerns identified by parents

Twenty-nine percent of parents from the random sample and 55 percent of parent from the targeted sample reported that they asked about an issue concerning their child's growth, development, learning, behavior, or mental health during the past 12 months (or past 18 months for targeted sample). Most of the parents who raised a concern during an appointment found that the information they received from their provider in response to their concerns was "very" or "somewhat" helpful (93% of parents from random sample, 91% from the targeted sample). However, 8 percent of parents from the random sample and 5 percent of parents from the targeted sample responded that the health provider "tried to address the concerns but was not helpful." Only one parent (a parent from the targeted sample) responded that the provider did not address the concern.

Referrals to specialists, community services, and early intervention services

Thirty percent of parents in the random sample received some type of referral during the previous 12 months. Parents who were part of the random sample were more likely to report being referred to other community services (19%) than specialists (13%) or early intervention services (10%) (Figure 13). Dual referrals, meaning referrals made to more than one type of service, were reported by only 9 percent of parents.

Not surprisingly, parents of the target group reported more referrals overall – with 75 percent receiving some type of referral (elevated screening and/or referrals were criteria for inclusion in the targeted group). These parents were also more likely to have their child referred to early intervention services (50%) than medical specialists (48%) or other community services (30%) (Figure 14). Dual referrals occurred more frequently (40%, compared to 9% of parents in the random sample).

Not all parents of the target group reported receiving a referral. This could be because their child may have received an elevated screening and not been referred, or the parents may not be aware that their child was referred.

For both samples, at least half of the parents reported their child received the service(s) to which they were referred (Figures 13-14; see figure 15 for baseline data).

Type of referrals and services received in past 12 months (Random sample) (N=91)

	Received	l Referral	Received	Services
	Number	Percent	Number	Percent
Specialist	12	13%	12	100%
Early intervention services/Help Me Grow	9	10%	5	63%
Other community services	17	19%	9	53%
Any of the above referrals	27	30%	21	78%
More than one type of referral	8	9%	6	75%

Note: Of those who received more than one type of referral (N=8), three children were given all three referrals (specialist, community services, and early intervention services), three received referrals to early intervention services and community services, and two were referred to a specialist and community services.

14. Type of referrals and services received in past 18 months (Targeted sample, N=40)

	Received	l Referral	Received	Services
	Number	Percent	Number	Percent
Specialist	19	48%	17	89%
Early intervention services/Help Me Grow	20	50%	13	65%
Other community services	12	30%	6	50%
Any of the above referrals	30	75%	24	80%
More than one type of referral	16	40%	9	56%

Note: Of those who received services (N=16), five children were given all three referrals (specialist, community services, and early intervention services), seven received referrals to early intervention services and community services, two were referred to a specialist and community services, and two were referred to early intervention services/Help Me Grow and community services.

The 2011 baseline interview was conducted in the early stages of the ABCD III project, before the pilot sites had implemented or formalized their screening and referral practices. In comparing the baseline results to the 2012 random sample, the data suggests referrals to early intervention services/Help Me Grow increased over time, from 40 percent at baseline to 61 percent in 2012 (Figures 13 and 15). Dual referrals were reported less among parents interviewed in 2012, compared to those interviewed at baseline (9% of parent interviewed in 2012, compared to 32% at baseline). However, because of the limitations already described about making comparisons over time and the small numbers of referrals made in the respective categories overall, this trend should be interpreted with caution.

15. Type of referrals and services received in past 12 months (2011 baseline)

	Received	l Referral	Received	Services
	Number	Percent	Number	Percent
Specialist	22	18%	20	91%
Early intervention services/Help Me Grow	10	8%	4	40%
Other community services	18	15%	10	56%
More than one type of referral	40	32%	7	18%

Note: Of those who received more than one type of referral (N=4), two children were given all three referrals (specialist, community services and early intervention services) one received a referral to early intervention services and a specialist, and another was referred to community services and a specialist.

Types of referrals made, by site

Patterns in the type of referrals made by each clinic should also be interpreted with caution, due to the relatively small number of parents in each sample. While there is variation in the rate of referrals to specialists, community services, and early intervention services by site, this may not be reflective of referrals made for each clinic's general patient population (Figures 16-17).

16. Types of referrals, by site (Random sample)

	Fridley	North Metro	Mayo	Duluth	White Bear Lake	Total	2011 Baseline Total
	(N=28)	(N=7)	(N=16)	(N=10)	(N=29-30)	(N=90-91)	(N=125)
Specialist	4%	2	19%	20%	13%	13%	18%
Community services	18%	3	19%	20%	14%	19%	15%
Early intervention services/ Help Me Grow	18%	3	6%		-	10%	8%

Note: Percentages are not reported for clinics with fewer than 10 respondents.

17. Types of referrals, by site (Targeted sample)

				White	
	Fridley	Mayo	Duluth	Bear Lake	Total
	(N=7-8)	(N=14)	(N=8)	(N=9-10)	(N=38-40)
Specialist	4	64%	4	22%	49%
Community services	-	57%	2	22%	32%
Early intervention services/Help Me Grow	4	50%	3	60%	50%

Note: Percentages are not reported for clinics with fewer than 10 respondents.

Types of referrals made, by age

There was variation in the rate of referrals to specialists, early intervention services, and community services by age groupings in the random sample. Younger children (under age 3) were more likely to be referred to a specialist (15%) than older children age 3 through 5 (6%). In contrast, older children, age 3 through 5, were more likely to be referred to early intervention services (25%) than children under age 3 (7%) (Figure 18).

18. Types of referrals, by age (Random sample)

	Under age 3	Age 3-5	Total	2011 Baseline Total
	(N=73-74)	(N=16-17)	(N=90-91)	(N=125)
Referred to specialist	15%	6%	13%	18%
Referred to early intervention services/Help Me Grow	7%	25%	10%	8%
Referred to community services	18%	24%	19%	15%

In the targeted sample, there was less variation in referrals made by age. Referrals to specialists, community services, and early intervention services were all relatively common (43%-57% of children were referred to each type of service). Although older children were more likely to be referred to early intervention services, referrals to this type of service were relatively common for both age groups (54% of children age 3-5 were referred, compared to 43% of younger children) (Figure 19).

19. Types of referrals, by age (Targeted sample)

	Under age 3	Age 3-5	Total
	(N=13-14)	(N=25-26)	(N=38-40)
Referred to specialist	57%	44%	49%
Referred to early intervention services/Help Me Grow	43%	54%	50%
Referred to community services	46%	24%	32%

Respondents' experience with referrals

Additional analyses were run to assess the alignment between concerns raised during the appointment and referrals given to the family and are reported in the following subsections. Responses to additional questions about the assistance families received during the referral process and their overall perceptions of the referral made are included in the Appendix (Figures A15-A26).

Early intervention services

Of those respondents who said that their health provider noted a concern about their child's development (N=21 for the random sample and N=20 for the targeted sample), 30

percent of the random sample and 70 percent of the targeted sample said they received a referral to early intervention services.

Of those who said that their health provider noted a concern about their child's mental health, two of seven children from the random sample and seven of eight children from the targeted sample received a referral to early intervention services.

When parents where asked why they did not receive services following a referral to early intervention, four said there was no particular reasons they have not acted on the referral. One said that "it's my first child so I don't know what to look for." Another respondent said, "[B]oth of my kids have been on the edge of getting services. My son needs them [...] but he doesn't qualify."

Specialists

- Of those parents whose clinic doctor or health provider noted a concern about their child's learning or development (N=21 for random sample and N=20 for targeted sample), 38 percent of the random sample and 75 percent of the targeted sample received a referral to a specialist.
- Two of the seven respondents from the random sample (29%) and five of the eight respondents from the targeted sample (63%) whose clinic doctor or health provider noted a concern about their child's behavior or mental health received a referral to a specialist.

Other community services

Parents received referrals for a variety of community services including Early Childhood Family Education (n=14), public health (n=8), Head Start (n=5), preschool (n=3), Early Childhood Special Education (n=2), and a variety of others such as WIC, county disability services, home visiting, physical therapy, and parenting.

Other linkages to benefits and resources

Parents were also asked specifically about whether their clinic provided them with information about public benefits or other resources. Over half (60% of parents from the random sample and 53% of parents from the targeted sample) reported they received those types of resources (Figures 20-21).

20. Other linkages to resources through primary care clinics (Random sample)

	Fridley (N=28)	North Metro (N=7)	Mayo (N=16)	Duluth (N=9)	White Bear Lake (N=29)	Total (N=89)	2011 Baseline Total (N=122)
Received information from clinic about other public benefits such as Food Stamps, WIC or other resources that may be helpful to your family	46%	6	81%	3	62%	60%	54%

Note: Percentages are not reported for clinics with fewer than 10 respondents.

21. Other linkages to resources through primary care clinics (Targeted sample)

	Fui all a	Ma	Deeleetle	White Bear	Total
	Fridley	Mayo	Duluth	Lake	Total
	(N=8)	(N=14)	(N=8)	(N=10)	(N=40)
Received information from clinic about other public benefits such as Food Stamps, WIC or other resources that may be					
helpful to your family	2	71%	4	50%	53%

Note: Percentages are not reported for clinics with fewer than 10 respondents.

Respondents' experience with care coordination services

Another goal of the ABCD III project was to enhance care coordination across the various services families receive. It should be noted that families may or may not be aware of whether or not they are receiving care coordination. To clarify what is meant by "care coordination" respondents were asked:

"Is there someone at the clinic 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? This person is sometimes called a "Care Coordinator."

Overall, 10 percent of the random sample and 17 percent of the targeted sample responded that they are currently receiving care coordination services through their clinic. Although the survey did ask parents to report the perceived helpfulness of these services, the perspectives from a larger number of parents are needed before conclusions can be made.

Of those respondents who said that their health provider noted a concern about their child's development (N=21 for the random sample and N=20 for the targeted sample), 24 percent of the random sample and 20 percent of the targeted sample had a care coordinator.

Of those respondents who said that their health provider noted a concern about behavior or mental health (N=7 for the random sample and N=8 for the targeted sample), one child from the random sample and 3 children from the targeted sample had a care coordinator.

Some respondents (8% of the random sample and 11% of the targeted sample) felt they needed someone to coordinate their child's care.

22. Care coordination services (Random sample)

	Fridley (N=26,28)	North Metro (N=6-7)	Mayo (N=14,16)	Duluth (N=10)	White Bear Lake (N=29-30)	Total (N=85,91)	2011 Baseline Total (N=125)
Feel they need someone to coordinate care among child's doctors and services	14%	1	6%	-	3%	8%	6%
Currently receiving care coordination through their clinic	4%	4	14%	-	7%	11%	10%

Note: Percentages are not reported for clinics with fewer than 10 respondents.

23. Care coordination services (Targeted sample)

				White	
	Fridley	Mayo	Duluth	Bear Lake	Total
	(N=4,7)	(N=13-14)	(N=8)	(N=10)	(N=35,39)
Feel they need someone to coordinate care among					
child's doctors and services	4	21%	3	10%	28%
Currently receiving care coordination through their clinic	1	15%	2	10%	17%

Other comments

Parents were also asked to describe examples of ways their clinic coordinates with other community services and ways this coordination could be improved. A number of respondents did provide examples with information they had received in their clinic or ways that their provider shared information with their child's school or other specialists. However, some parents were interested in receiving more information about other services, greater coordination in scheduling appointments, improved communication with other services, or offered other suggestions about ways to improve service coordination (see the Appendix for a full list of all parent comments).

Appendix

Additional data tables

Demographic information

A1. Age of respondents' child (Random sample)

	Fridley	North Metro	Mayo	Duluth	White Bear Lake	Total	2011 Baseline Total
	(N=28)	(N=7)	(N=16)	(N=10)	(N=30)	(N=91)	(N=125)
Birth to 11 months	39%	1	-	40%	37%	30%	2%
12 to 18 months	18%	3	-	20%	33%	22%	18%
19 to 23 months	14%	-	56%	10%	-	15%	30%
2 years old	4%	-	44%	10%	13%	14%	27%
3 years old	4%	3	-	10%	7%	8%	14%
4 years old	18%	-	-	10%	7%	9%	5%
5 years old	4%	-	-	-	3%	2%	4%

Note: Percentages are not reported for clinics with fewer than 10 respondents.

A2. Age of respondents' child (Targeted sample)

	Fridley	Mayo	Duluth	White Bear Lake	Total
	(N=8)	(N=14)	(N=8)	(N=10)	(N=40)
Birth to 11 months	0	7%	0	-	3%
12 to 18 months	0	7%	0	-	3%
19 to 23 months	0	7%	2	-	8%
2 years old	2	21%	3	10%	23%
3 years old	5	36%	2	30%	38%
4 years old	1	14%	0	50%	20%
5 years old	0	7%	1	10%	8%

A3. Racial or ethnic background of child (Random sample)

	Fridley (N=28)	North Metro (N=7)	Mayo (N=16)	Duluth (N=9)	White Bear Lake (N=30)	Total (N=90)	2011 Baseline Total (N=125)
African American	21%	-	25%	2	13%	18%	15%
American Indian	4%	_	-	-	-	1%	<1%
Asian	7%	1	-	-	7%	6%	5%
Hispanic/Latino	18%	1	25%	1	23%	20%	16%
White/Caucasian	68%	7	81%	7	83%	79%	78%
Other	4%	-	6%	-	-	2%	2%

Note: Percentages are not reported for clinics with fewer than 10 respondents.

A4. Racial or ethnic background of child (Targeted sample)

				White	
	Fridley	Mayo	Duluth	Bear Lake	Total
	(N=8)	(N=14)	(N=8)	(N=10)	(N=40)
African American	1	21%	1	30%	20%
American Indian	-	-	-	10%	3%
Asian	2	-	-	20%	10%
Hispanic/Latino	2	14%	-	-	10%
White/Caucasian	3	57%	7	70%	64%
Other	-	7.1%	-	_	3%

Note: Percentages are not reported for clinics with fewer than 10 respondents.

A5. Respondent's distance to clinic (Random sample)

	Fridley (N=27)	North Metro (N=7)	Mayo (N=16)	Duluth (N=10)	White Bear Lake (N=30)	Total (N=90)	2011 Baseline Total (N=124)
Less than 25 miles	89%	6	13	90%	90%	88%	86%
26 to 50 miles	11%	-	3	-	10%	10%	12%
51 to 100 miles	-	1	-	10%	-	2%	2%
More than 100 miles	-	-	-	-	-	-	-

A6. Respondent's distance to clinic (Targeted sample)

	Fridley	Mayo	Duluth	White Bear Lake	Total
	(N=8)	(N=14)	(N=8)	(N=9)	(N=39)
Less than 25 miles	8	86%	7	9	92%
26 to 50 miles	-	7%	1	0	5%
51 to 100 miles	-	-	0	0	
More than 100 miles	-	7%	0	0	3%

Note:

Percentages are not reported for clinics with fewer than 10 respondents.

A7. Length of time child seen at clinic (Random sample)

	Fridley (N=28)	North Metro (N=6)	Mayo (N=15)	Duluth (N=10)	White Bear Lake (N=29)	Total (N=88)	2011 Baseline Total (N=122)
Less than 6 months	21%	-	7%	30%	21%	18%	2%
6 months to 1 year	25%	-	-	70%	24%	24%	9%
More than 1 year	54%	6	93%	-	55%	58%	87%

Note:

Percentages are not reported for clinics with fewer than 10 respondents.

A8. Length of time child seen at clinic (Targeted sample)

				White	
	Fridley	Mayo	Duluth	Bear Lake	Total
	(N=7)	(N=13)	(N=8)	(N=10)	(N=38)
Less than 6 months	-	-	_	-	-
6 months to 1 year	-	15%	_	10%	8%
More than 1 year	7	85%	8	90%	92%

Note:

A9. Total number of visits in the past 12 months (Random sample)

	Fridley (N=28)	North Metro (N=7)	Mayo (N=16)	Duluth (N=10)	White Bear Lake (N=30)	Total (N=91)	2011 Baseline Total (N=125)
1 time	7%	2	-	30%	-	8%	9%
2 to 3 times	11%	1	56%	10%	40%	29%	41%
4 to 10 times	75%	3	44%	60%	53%	58%	41%
More than 10 times	7%	1	-	-	7%	6%	10%

Note:

Percentages are not reported for clinics with fewer than 10 respondents.

A10. Total number of visits in the past 18 months (Targeted sample)*

				White	
	Fridley	Mayo	Duluth	Bear Lake	Total
	(N=7)	(N=14)	(N=8)	(N=9)	(N=38)
1 time	0	7%	1	2	11%
2 to 3 times	3	29%	5	4	42%
4 to 10 times	4	43%	2	2	37%
More than 10 times	0	21%	0	1	11%

Note: Percentages are not reported for clinics with fewer than 10 respondents.

A11. Number of well-child visits or check-ups (Random sample)

	Fridley (N=28)	North Metro (N=7)	Mayo (N=16)	Duluth (N=10)	White Bear Lake (N=30)	Total (N=91)	2011 Baseline Total (N=125)
None	-	-	-	-	-	-	4%
1 time	25%	5	25%	20%	10%	23%	30%
2 or 3 times	36%	1	63%	50%	50%	45%	35%
3 or more times	40%	1	13%	30%	40%	32%	31%

Note:

^{*}As mentioned previously in the methods section, the look back period for parents in the targeted sample was 18 months rather than 12 months. This was done to match the timing of ABCD III implementation activities. The look back period for parents in the random sample was 12 months to match the way questions were asked of the random sample at baseline.

A12. Number of well-child visits or check-ups (Targeted sample)

	Fridley	Mayo	Duluth	White Bear Lake	Total
	(N=8)	(N=14)	(N=8)	(N=9)	(N=39)
None	-	14%	-	-	5%
1 time	2	21%	3	3	28%
2 or 3 times	5	36%	4	4	46%
3 or more times	1	29%	1	2	21%

Note:

Percentages are not reported for clinics with fewer than 10 respondents.

A13. Primary language spoken in the home (Random sample)

	Fridley (N=28)	North Metro (N=7)	Mayo (N=16)	Duluth (N=10)	White Bear Lake (N=30)	Total (N=91)	2011 Baseline Total (N=125)
English	64%	6	75%	90%	87%	78%	86%
Spanish	18%	1	13%	10%	3%	11%	10%
Hmong	-	-	-	-	-	-	-
Vietnamese	-	-	-	-	7%	2%	-
Somali	4%	-	13%	-	-	3%	<1%
Other	14%	-	-	-	3%	6%	4%

Note:

Percentages are not reported for clinics with fewer than 10 respondents.

A14. Primary language spoken in the home (Targeted sample)

	Fridley	Mayo	Duluth	White Bear Lake	Total
	(N=8)	(N=14)	(N=8)	(N=10)	(N=40)
English	4	71%	8	100%	80%
Spanish	2	21%	-	-	13%
Hmong	_	-	-	-	-
Vietnamese	1	-	-	-	3%
Somali	-	-	-	-	-
Other	1	_	-	-	5%

Note:

Clinic assistance with referrals to early intervention, specialists, and community services

A15. Assistance with referrals to early intervention services in the past 12 months (Random sample)

	Fridley (N=5)	North Metro (N=3)	Mayo (N=1)	Duluth (N=0)	White Bear Lake (N=0)	Total (N=9)	2011 Baseline Total (N=9-10)
Clinic doctor or staff did something to assist in referral beyond giving early intervention services/Help Me Grow contact information	3	1	-	-	-	4	30%
Clinic doctor or staff followed-up to find out if child was getting early intervention services*	3	2	-	-	-	5	5

^{*} Of those receiving a referral to early intervention services/Help Me Grow (N=9), 5 had received those services at the time of the interview.

Note: Percentages are not reported for clinics with fewer than 10 respondents.

A16. Assistance with referrals to early intervention services in the past 18 months (Targeted sample)

	Fridley (N=2-4)	Mayo	Duluth	White Bear Lake	Total (N=17-20)	
		(N=7)	(N=3)	(N=5-6)		
Clinic doctor or staff did something to assist in referral beyond giving early intervention services/Help Me Grow contact information*	2	4	1	1	40%	
Clinic doctor or staff followed-up to find out if child was getting early intervention services*	1	5	2	3	65%	

^{*} Of those receiving a referral to early intervention services/Help Me Grow (N=20), 13 had received those services at the time of the interview.

Note: Percentages are not reported for clinics with fewer than 10 respondents.

A17. Assistance with referrals to specialists in the past 12 months (Random sample)

	Fridley (N=1)	North Metro (N=2)	Mayo (N=3)	Duluth (N=2)	White Bear Lake (N=4)	Total (N=12)	2011 Baseline Total (N=19-22)
Clinic contacted the specialist directly*	-	2	2	2	3	75%	41%
Clinic doctor or staff asked about appointment with specialist/followed-up*	1	2	2	2	3	83%	73%

^{*} Of those receiving a referral to a specialist (N=12), 12 had received those services at the time of the interview. For baseline sample, 22 were referred to a specialist. Of those, 20 had received services at the time of interview, and 2 were going to receive services in the near future.

A18. Assistance with referrals to specialists in the past 18 months (Targeted sample)

				White Bear	ar	
	Fridley	Mayo	Duluth	Lake	Total	
	(N=4)	(N=9)	(N=4)	(N=2)	(N=19)	
Clinic contacted the specialist directly*	2	7	4	1	74%	
Clinic doctor or staff asked about appointment with						
specialist/followed-up*	2	6	2	2	63%	

Of those receiving a referral to a specialist (N=19), 17 had received those services at the time of the interview, and 2 planned to receive specialist services in the near future.

Note:

Percentages are not reported for clinics with fewer than 10 respondents.

A19. Assistance with referrals to community services (other than Help Me Grow) in the past 12 months (Random sample)

	Fridley (N=5)	North Metro (N=3)	Mayo (N=3)	Duluth (N=2-3)	White Bear Lake (N=4-5)	Total (N=16-17)	2011 Baseline Total (N=18)
Clinic doctor or staff helped you receive services from community agencies beyond the referral	-	2	2	-	1	29%	44%
Clinic doctor or staff asked about community services received/followed-up*	1	2	-	-	1	25%	56%

^{*} Of those receiving a referral to community services (N=17), 9 had received those services at the time of the interview, and 6 planned to receive services in the near future.

Note:

Percentages are not reported for clinics with fewer than 10 respondents.

A20. Assistance with referrals to community services (other than Help Me Grow) in the past 12 months (Targeted sample)

				White Bear		
	Fridley	Mayo	Duluth	Lake	Total	
	(N=0)	(N=8)	(N=2)	(N=2-3)	(N=12-13)	
Clinic doctor or staff helped you receive services from community agencies beyond the referral	-	1	1	-	17%	
Clinic doctor or staff asked about community services received/followed-up*	-	3	2	1	46%	

^{*} Of those receiving a referral to community services (N=12), 6 had received those services at the time of the interview, and 2 planned to receive services in the near future.

Note:

Respondents' perceptions of referrals made

A21. Perceptions of child's referral to early intervention services (Random sample)

					2011 Baseline Total (N=10)*		
N= 9	Strongly disagree	Disagree	Agree	Strongly agree	Agree	Strongly agree	
The reasons why my child was referred to early intervention services were explained to me.			3	6	50%	50%	
	-	<u>-</u>	<u>J</u>	0	30 /6	30 /0	
I have a right to approve all early intervention services my child receives.	-	-	4	5	50%	50%	
My questions about the referral were answered in a timely manner.	-	-	3	6	60%	40%	
I feel this was an appropriate referral for my child.	-	-	5	4	70%	30%	

^{*}No respondents strongly disagreed or disagreed with the questions.

Note:

Percentages are not reported for clinics with fewer than 10 respondents.

A22. Perceptions of child's referral to early intervention services (Targeted sample)

N=19-20	Strongly disagree	Disagree	Agree	Strongly agree
The reasons why my child was referred to early intervention services were explained to me.	-	5%	35%	60%
I have a right to approve all early intervention services my child receives.	-	-	40%	60%
My questions about the referral were answered in a timely manner.*	-	-	37%	63%
I feel this was an appropriate referral for my child.	5%	-	32%	63%

A23. Perceptions of child's referral to a specialist (Random sample)

					2011 Baseline Total (N=22)*		
N=12	Strongly disagree	Disagree	Agree	Strongly agree	Strongly disagree	Agree	Strongly agree
The reasons why my child was referred to a specialist were explained to me.	_	8%	8%	83%	9%	32%	59%
I have a right to approve all specialist services my child receives.	-	-	25%	75%	9%	18%	73%
My questions about the referral were answered in a timely manner.	-	-	25%	75%	9%	41%	50%
I feel this was an appropriate referral for my child.	8%	-	17%	75%	10%	33%	57%

^{*}No respondents disagreed with the questions.

A24. Perceptions of child's referral to a specialist (Targeted sample)

N=18-19	Strongly disagree	Disagree	Agree	Strongly agree	
The reasons why my child was referred to a specialist were explained to me.	-	-	32%	68%	
I have a right to approve all specialist services my child receives.	-	-	32%	68%	
My questions about the referral were answered in a timely manner.	-	-	32%	68%	
I feel this was an appropriate referral for my child.*	-	-	22%	78%	

A25. Perceptions of child's referral to community services (Random sample)

					2011 Baseline Total (N=18)*		
N=16	Strongly disagree	Disagree	Agree	Strongly agree	Disagree	Agree	Strongly agree
The reasons why my child was referred to community services were explained to me.	-	-	50%	50%	6%	39%	56%
I have a right to approve all community services my child receives.	-	-	42%	56%	6%	17%	78%
My questions about the referral were answered in a timely manner.	-	-	50%	50%	6%	44%	50%
I feel this was an appropriate referral for my child.	-	6%	38%	56%	11%	44%	44%

^{*}No respondents strongly disagreed with the questions.

A26. Perceptions of child's referral to community services (Targeted sample)

N=13	Strongly disagree	Disagree	Agree	Strongly agree
The reasons why my child was referred to community services were explained			E40/	500 /
to me.	-	-	54%	52%
I have a right to approve all community				
services my child receives.	-	-	54%	46%
My questions about the referral were				
answered in a timely manner.	-	-	54%	46%
I feel this was an appropriate referral for				
my child.	-	-	39%	62%

Open ended responses

The clinic is looking to improve the way it coordinates service with other medical providers, the schools, and in the community. Have you noticed any examples of this type of coordination happening in the past year?

Food and other supports:

Yes. They talk about all the different programs and stuff that are available--like, examples--like the WIC, the food support programs that are available in the community; they have many kinds of different resources and stuff they have available. Any time I need any kind of help or assistance they're always helping me out and assigning resources and programs that help me out. They're a great clinic or resource for assigning things. When I need formula or things like that, they're always available to help track down places or things to help me find, like, a mattress for my son. They help find gift certificates and stuff for me if I'm low on food. They help find--like, they tell me about food shelf programs, they have a mental health coordinator that's there that I work with. Those are some examples of things that are there. They're just great.

Yes. Information about food stamps, health insurance.

Yes, they refer us to the specialist if we need one they referred us to WIC.

The clinic was where I found out about WIC but it was more than a year ago.

Brochures, flyers, and dissemination of information/services:

Nothing has been said directly to me but there are brochures and information available on the wall.

They've got a mental health provider who they've added to their clinic who works with children and is focused on family care. They've got many resources (flyers) available in the lobby. They've got them in Spanish and English. Not just focused on certain aspects of the community. They have car-seat drives and winter clothes drive as well.

Well they just mention all the resources available in the community, but nothing beyond that.

On the wall there are brochures about Childcare Resource & Referral. That's all that I have noticed.

Yes, they just have posters and flyers the clients have access to.

Yes, work with the pharmacy and send out newsletter about things that are happening in the community.

They have pamphlets in the waiting room.

With my new child, my 4 month old, they had someone come in and explain all the different types of services I could receive and they gave me lots of flyers for the different organizations.

Yes, they gave me better services than before, as far as giving me resources names so I can get in touch with the things I needed.

Yes, they always have surveys available to provide suggestions. They also have car seats at clinics. They also offer classes for parents who have children with behavioral issues.

School-related:

A little bit, they give me numbers to get my four year old into school for testing so I could get him in sooner. They gave me programs where I could put him in during school.

They coordinated very well with the school district in meeting my child's needs for special education.

When they referred us to the coordinators of the public school, just to testing her to see her abilities and skills, the second visits they explain why they were testing her and they explained me ways to improve her skills that was very helpful.

Health-related:

Not with [this child] but with other children. We have two children with autism and they get referrals and checks as far as speech and motor skills things of that nature, they keep a close eye because it's in the family.

Yes I have. My older child has large special needs. They suggested some coordination and we are working on that-something called home doctor. I haven't actually done it, but we have talked about it.

Just a reminder call to get a Child Wellness Check Up appointment. I think the county called me on behalf of the clinic.

Yeah I have. They have "my chart" at the clinic for everybody and they can go online and see what the doctors have said about their child's care.

Yes, they're very helpful. When you go into the doctor's office, you don't have to wait long, only a minute. Any questions that you ask them, they are very helpful.

Yes, the clinic has written notes that we needed written for my other children. They have been helpful with the IEPs. They've helped with the best behavior specialist in the State. They helped with diagnosis for our other child on autism spectrum. They loved going to the doctor, because they can communicate with the child. All the doctors are like this. From the 1st time years ago, I went to this clinic. I drive from Elk River to Fridley because I won't change.

Yes, they work closely with his ENT [ears/nose/throat] specialist. He has had tubes put in his ears.

Receiving information, if I have questions about things, my doctor is really good about giving me numbers and resources to call. In my first year, my son had medical problems and they helped me with this.

General comments:

Yes, we have outreach and coordination of services for another child.

I have, they have a bunch more stuff for kids' like books or information.

Yes, they are helping with forms and coordination of services.

We only see one pediatrician. She has always been a champion for community services. She always lets us know what is out in the community. We have been going to her for 18 years.

No (N=87)

Do you have any suggestions for ways in which your clinic could be more helpful in coordinating with other services?

Appointments:

For the clinic to see children without an appointment. Children just get sick all of a sudden and need to see the doctor/nurse.

Maybe like, sometimes I need to make an appointment that is not documented in their system and they are not sure why I am making that appointment.

I do not because I love it all. I'm always able to get my kids in, they do it all and on time.

Care coordination:

If they had a coordinator, it would be nice to have someone that has everything on my son since he is in Head Start, school system special program, and doctor's visits. If I could just sign one form and have them all communicate that would be great.

If a child has multiple specialists there should be a care coordinator especially for scheduling appointments.

I can't think of anything right now there is always room for improvement. It would be helpful if there was better coordination of care.

I guess it would be like, maybe, sit down and make, like, you know, not necessarily a written contract, but maybe something that works with everyone so they're being followed up on and communicating about the child's care-especially if they're seeing a specialist. Unless I bring it up, they don't even ask how he's doing. My son is hearing impaired and speech impaired, so he sees 2 different specialists. He's had surgeries and they never follow up with that information or see how he's progressing with speech or hearing unless I bring it up. When I go to the doctor's office, I'm lucky if they even know who we are. I sometimes feel like maybe if they interacted more with the specialists and talked more about, like, living situation, financial situation, and asked about how we're doing as parents. Like, you were talking about WIC earlier, just, as a parent going into a doctor's office with a slew of kids behind you, you don't have time to read the walls or bring it up.

Consolidate the specialties in one building:

They could check in a lot more than they do and they could use one system they sent you to different places instead of having all the pediatric specialists in one building.

It would be really nice if they were all in one building. They have pediatrics in Baldwin, but no audiologist and when they schedule an appointment for a child's naptime. It is not a fun day. Free Parking. The price was phenomenal and that was one of our reasons for switching to a different clinic.

Communication:

They could have the parents sign an authorization that the school and clinic can share information.

If the patient goes to a different clinic--that their doctor can see what is on their record. Only a few clinics do that now. Not all clinics have that. I had to go get shots. One lady couldn't see this information on my child's chart, but the other one did see this info. It was hard.

Online service from the clinic that you could go on, and refresher of the information you received at the clinic. A lot of time you get so much information at your appointment that it is hard to remember it. It would be nice to have a referral of it all.

Maybe an online program where a parent could see all the services their child is getting at the same website page.

I like how everybody gathers around and talk about it. How everybody gets together to answer questions when it's surgery time and I needed to schedule an appointment. Everybody takes notes and they give the notes to the doctors that could not be there.

Staffing:

The dermatologist was not available for two months, and my child's condition was too serious. It was very traumatizing for me. I wish that they could have provided me with quicker services that I could use for my child's condition at the moment.

I think they are understaffed.

One time, we actually wanted a female interpreter but got a male interpreter, and the clinic didn't tell us that there were no female interpreters, that delayed the appointment for two weeks. If they could call us and let us know before her appointment.

No. I think, our main pediatrician is pretty educated, the things that our family need and suited. Our pediatrician and midwife are very educated in their field; they taught us a lot, when we are also in that same field. I have two children with autism and it went a long way, and before it happened to our family we didn't know about it, my wife is a nurse and my kids did used intervention and we learned a lot and they know more than we do.

They were better than the other clinic in town. A doctor refused to see us if we didn't do what he said, we wanted to adjust the shot schedule and he wouldn't see us. We had a great doctor before, but he was transferred to head a pediatric department. I like to make decisions and talk it over with the doctor.

Their pediatrics are awesome, I love the clinic that they go to. I have a son who is special needs and his doctor is always 100% available to my kids. He is awesome.

[The doctor] listens so intently to the needs of the family and the children, the whole family, and has helpful suggestions for the family. She seemed to have a knowledgeable working relationship with specialists and community agencies that she put us in contact with. I wish every child could have her as a doctor.

Not much, not really. I am very happy with his doctor. He seems to care a lot for my kids and he did a great. My oldest son had IPP and [the doctor] actually stepped in to check in on him even when he was not his doctor at that time. My youngest son the one you are talking about went through heart surgery because his doctor heard his heart murmuring and children's hospital was surprised that his doctor heard it even when he didn't have any symptoms.

Services/resources:

If they took more time to know where the kids are going to school, because I did not know where to go to get my child's preschool screening. This was a real stumbling block. If they could have a brochure or written down the number for me to call to make that screening appointment.

Any type of brochure especially about preschool, because I don't know much about preschool. Information about whether she is ready for preschool--like what to look for.

Well, they could work with WIC a little bit better, as far as what they give out in food. They give me way too much juice and according to her doctor that is too much per month.

Maybe different resources, like if we're struggling to either feed the child or pay our bills or different resources we can have, like play groups anything in the community that would help our kids' growth or just health. Maybe if they have those resources, instead of just leaving them on a bulletin board, bring those up in a doctor's office or ask how things are at home; give us an opportunity to have those resources because unless you actually research it there's really nothing out there. I come across people all the time who are struggling who have no idea that there's help out there for them. It would be nice to have those resources offered to you or questions asked, "Do you need this," "How's it going at home," those general questions... I think it would be helpful in the long run for people who are struggling because the economy is struggling and there are people who need help. Our pediatrician is who we're going to, especially those first two years. It would be nice to have more support and communication with the people we deal with so we don't have to keep saying the same things and telling the same stories to everyone we deal with.

I don't know whether or not they have a bulletin board outside in the lobby where we wait and whatnot, but if they don't, I would say put it up there, and if not, I guess also work--whether in our meeting... but I already have those things, so--I actually don't remember whether or not his doctor actually offered those types of things because I already had that all set. If anything, those things on the bulletin board. Things where, the government--so, like, food stamps and cash... And when I was at WIC, they actually told me, I remember hearing this from my friend, as well, WIC refreshed my memory of the food shelter and--what's that thing called? The one at the church at Central and... do you know? You go and pay 15 dollars and whatever you can carry for food... Ruby's? Rudy's? Whatever you can carry for food is what you take home, is what you need. Do you know what I'm talking about? Basically, the 15 dollars is for transportation for bringing the food, maybe from Superior, Wisconsin, maybe from the Cities. I don't remember. WIC actually reminded me of that, of the food shelter. Do you know, at the farmer's market they take EBT? I don't know whether or not you know that. She gave me a booklet of like programs for children to go through so I guess more--not at his age but more five years old and whatnot--community things to do for children, especially in the summertime, which is nice--I don't need it personally at this moment, but it's still nice to know.

No because I don't really know what other services are out there or need them. Maybe they could mention what services are out there.

Their information seems pretty general in terms of county and state services. Something more in-depth would be helpful.

Maybe they should put information up in the waiting area if they don't already have it.

Maybe letting you know about services that are provided at the time you check in.

I've been really satisfied with the services I get there. Everywhere I go I see promotions about the services they provide at WIC, at the childcare resources places, the department of Health--the MA places.

No they do a good job.

Brochures, flyers, applications, and handouts:

Maybe they could leave brochures for their clients.

Maybe providing more flyers pamphlets about what they are planning on doing. I'm the kind of person that does read flyers, pamphlets and other stuff that the clinics have available. It would be nice to have some in Spanish.

That would be super, even having the brochures available and contact information available. Names & phone numbers for the different agencies out there would be helpful. It is the parents' responsibility to make these calls.

Maybe have applications or information referrals in the waiting room about other school, community and other programs.

Maybe giving hand out of services offered in the community when they tell you -- you don't always remember. If you had a document/list of service that would be helpful in remember the services.

General comments:

Any time I have asked for something the clinic has been 100% hands-on. They are excellent about that.

No I think we have a really awesome clinic. I'm really impressed with their care.

No, they do a very good job. I don't have a complaint.

Nope, I love the clinic they are very helpful and answer any question that I have.

I am really happy with their services at this moment,

No, I think they do a good job.

No (N=65)

Is there anything else you would like to tell us that we have not asked?

General comments:

They are amazing and I truly love the service we get they take their time and answer all questions I am very happy.

Nope -- the clinic is better than [the clinic we went to before] -- very professional and friendly and feels like family there.

No I think they are pretty great. I've had really great experiences because I get all my questions answered. They are very helpful.

I would recommend this clinic to anybody who has a small child. I always tell my friends to go to this clinic.

I'm pretty satisfied with [the clinic].

We're very happy with the clinic.

I think they are very good.

No. It is a really a good place to go and I would refer it to anybody.

No. I have been very happy with the clinic especially in the children's area.

I hope they can get one doctor who can stay with him the whole time (for many years) and I like that clinic very much.

No. For them to continue their great service that they have there for us.

The [clinic] is the best in the world.

It's the only place I'd ever take him. I really like and trust that clinic!

They are a great clinic. We have stuck with them since day one and they'll be our clinic in the future.

No, they are excellent; they have always treated me with respect and are very nice and helpful.

No -- it is a good clinic and they are easy to talk to about your concerns or problems with the child.

Nope, I love the clinic that's why I have been going there for so long.

Staff, doctors, and nurses:

There is one doctor who has had me so upset that if she is the one on call I will just go to the emergency room instead of having to deal with her.

No. They are pretty good and efficient and nice. Except that they keep you on hold forever.

I am very happy with the clinic that I am going to now [to this clinic]. I love my doctor very much. I would not go somewhere else.

His personal doctor is excellent and takes time to answer questions. Most of the other doctors are also excellent.

No, but I think [this] is a good clinic. I think the doctor is a great physician. She's really calm and makes things clear for you.

I love [the clinic and am] happy with doctor.

They call me in to see the doctor right away, the wait is not long. They are a wonderful clinic and I appreciate everything they. God bless all of the staff there.

No. They are the ones to get us in HeadStart, early intervention. I give that clinic and pediatrician the credit.

We love our doctor.

I was really pleased there with the doctor's approach to all three of my kids.

No. I've been very happy with my doctor and the nurse practitioners.

The care for the boys. I have four boys and I couldn't ask for a better doctor for my boys. He is above and beyond. We have a 9 year old with 6 surgeries already and his provider is incredible.

No. We really appreciate his doctor and the services.

The staff at the clinic is helpful.

I would never change my clinic. I love my doctor. My doctor has been my pediatrician since I have been two. I have always loved my doctor.

I have a really great doctor -- hope he never leaves; everybody is nice and helpful.

Everybody at the clinic is very nice and they always make us feel very comfortable.

I love it at there. I love the clinic. I feel my son is comfortable every time I go there. Hearing stories from a friend with a child the same age, she had a different experience. My doctor is wonderful for him. When my child gets shots there, the nurses are really friendly and playful. They are good. Some people can upset the child before the shot, but they do a really good job.

Scheduling:

No. I love clinic. The doctors understand, they listen, and I am able to get my kids in on the day that I call. They are helpful; they give the kids tooth brushes and paste. If there is extra formula they give me that.

[The doctor] and the nurses are very attentive and get back to me right away, if I call. It's very easy to make appointments. If my child is sick they always work us in.

They have one of the best callbacks and the doctors work hard to see their regular patients.

No, never had a complaint. They are really good at helping me get in and addressing any issues or concerns that I have. The doctor is really good with my daughter.

Services:

We covered the gross motor skills. I wish they had done more with that.

I'm not sure about the question regarding a referral for behavior or mental health by the doctor. I haven't had that. If you want for example a blood test carried out for a child, because you want to know what is wrong. Is okay to ask for that? I'm wondering if this okay?

I got a referral to an asthma doctor. I've learned about when my daughter was first born, I was very nervous and very scared about feeling dumb about asking services that might not be out there. If they had this information on hand, brochures to give out at the appointments or lists of numbers on the websites, talking to parents with kids. The younger parents get very nervous about being judged by the people in the hospital or clinic, simply because they don't know what is out there, and afraid of being a bad parent. Some people are very judgmental, it is very stressful & frustrating to a young a parent.

Their service is good and very nice.

Language makes a difference so services like that helped a lot.

At [another clinic]...basically, you go in for your appointment, do whatever you need to and by the end of the appointment they just tell you what happened during that day. I wouldn't say like, an outline, but [something] like the shots you took today. Like a calendar type of thing. Like a Post-It note. I personally would [that in this clinic, too] so I can just put it in the folder so I can keep track myself. I don't know about others, but I like to stay organized. That's just me. I just kind of wanted a piece of paper.

No (N=75)

Interview instrument

Introduction: Part A

May I speak to [R] ?

ABCD-III (Assuring Better Child Development) Parent Interview: Follow-up

NAME OF CLINICS: Fridley Child and Teen Clinic, Fridley, North Metro Peds, Fridley, Mayo Pediatrics, Rochester, Health Partners – White Bear Lake, and Saint Luke's Pediatric Associates, Duluth

IF R IS NOT HOME: When would be the best time to reach[R]? MAKE NOTES ON FACESHEET
IF R IS AVAILABLE, PROCEED.
This is[Interviewer] calling from Wilder Research. This is not a sales call. We are calling about services your child received at [NAME OF CLINIC]. [NAME OF CLINIC] is part of an initiative with the Minnesota Department of Human Services to better meet the needs of families with young children – children age 5 and under. We are interested in learning more about your experiences at regular check-ups or well-child visits for your child. You may recall receiving a letter recently that explains our study. The interview takes about 15 to 20 minutes. To thank you for completing this interview, we will send you a \$15 gift card from either Wal-Mart or Target. Is now a good time?

IF R SAYS YES: Do you remember receiving a letter from Wilder Research explaining our study and your rights to privacy? Do you have any questions about it? Would you like me to explain them to you?

AS NEEDED: Anything you say during this interview will be kept confidential unless you tell us that you or someone else in your household is in immediate danger. Your answers will not be seen by anyone except the staff from Wilder Research who are working on the study. If there is a question you would rather not answer, just let me know that, and I will skip it and move on to the next question. This study will not affect your relationship with the clinic or any other services you may be receiving.

IF R SAYS NOW IS NOT A GOOD TIME: When would be a better time to reach you? MAKE NOTES ON FACESHEET.

IF R REFUSES: Is there any particular reason you prefer not to be interviewed? NOTE REASON FOR REFUSAL ON THE FACESHEET. Thank you for your time.

1.	Because this is a study of services to young children, can you tell me how old [NAME OF CHILD] is?				
		Birth to 11 months		1	
		12 to 18 months		2	
		19 to 23 months		3	
		2 years old		4	
		3 years old		5	
		4 years old		6	
		5 years old		7	
		Refused		7	
		Don't know		8	
FOF	R THEIR TIME, AND TERMINATE	EINTERVIEW].	INELIGIBLE FOR SURVEY, THANK THEM		
2.	Is [NAME OF CLINIC] the clinic	where [NAME OF CHILD] usually red			
			(GO TO Q. 5a)		
			(GO TO Q. 5a)		
		Don't know	(GO TO Q. 5a)	8	
3.	How long has [NAME OF CHIL	D] been a patient at this clinic? Would	d you say		
		Less than 6 months,		1	
		6 months-1 year or		2	
		More than one year?		3	
		Refused		7	
		Don't know		8	
4a.	Do you have a regular doctor o	r health provider for [CHILD'S NAME]	at [NAME OF CLINIC]?		
		Yes		1	
		No	(GO TO Q. 5a)	2	
			(GO TO Q. 5a)		
			(GO TO Q. 5a)		
4b.		your child's regular doctor, nurse pra-			
		Don't know		8	

	During the past 12 months (18 months for "Targeted sample"), how many times was [CHILD'S NAME] seen at [NAME OF CLINIC]? Would you say						
	1 time,						
	2 or 3 times,						2
	4 to 10 times, or .						3
	More than 10 tim	es?					
	Refused						
	Don't kn	w					8
5b.	How may of these visits, during the past 12 months check-up or well-child visit? Would you say	(18 months for "Targe	eted sam	ple"), we	re your cl	hild's reg	ular
	None,						
	·						
		ups or well child visits					
		OW					
	se next questions are related to your child's growth ar otional and mental health.	nd development. Later	, we will	ask you	some que	estions a	bout
6.	In the past 12 months (18 months for "Targeted sar the following to address [NAME OF CHILD]'s learni regular check-up or well child visit.						
	Did the doctor or other health provider		Yes	No	REF	DK	
	Note a concern about your child's learning or constant should be watched carefully?	levelopment that	1	2	7	8	
	b. Test your child's learning or development?		1	2	7	8	
	c. Refer your child for testing of his/her learning of	or development?	1	2	7	8	
	d. Refer your child for speech-language or hearing		4	2	_	8	
	d. Refer your child for speech-language of fleah	ig testing?	1	_	7	U	
	Have you fill out a questionnaire about specific observations you may have about your child's	concerns or	l		/	0	
	e. Have you fill out a questionnaire about specific	concerns or	1	2	7	8	
	Have you fill out a questionnaire about specific observations you may have about your child's	concerns or	-		·		
6f.	e. Have you fill out a questionnaire about specific observations you may have about your child's ability to communicate? IF NO FOR ALL Q. 6A-6E, GO TO Q. 7	concerns or	-		·		
6f.	e. Have you fill out a questionnaire about specific observations you may have about your child's ability to communicate? IF NO FOR ALL Q. 6A-6E, GO TO Q. 7 IF YES TO ANY Q. 6A-6E, CONTINUE Did you get any advice or plans for next steps?	concerns or	1	2	7	8	
6f.	e. Have you fill out a questionnaire about specific observations you may have about your child's ability to communicate? IF NO FOR ALL Q. 6A-6E, GO TO Q. 7 IF YES TO ANY Q. 6A-6E, CONTINUE Did you get any advice or plans for next steps? Yes	c concerns or physical abilities or	1	2	7	8	
6f.	e. Have you fill out a questionnaire about specific observations you may have about your child's ability to communicate? IF NO FOR ALL Q. 6A-6E, GO TO Q. 7 IF YES TO ANY Q. 6A-6E, CONTINUE Did you get any advice or plans for next steps? Yes	c concerns or physical abilities or	1	2 (GO	7 7 FO Q. 6h)	8	3
6f.	e. Have you fill out a questionnaire about specific observations you may have about your child's ability to communicate? IF NO FOR ALL Q. 6A-6E, GO TO Q. 7 IF YES TO ANY Q. 6A-6E, CONTINUE Did you get any advice or plans for next steps? Yes	c concerns or physical abilities or	1	2 (GO	7 TO Q. 6h)	8	
6f. 6g.	e. Have you fill out a questionnaire about specific observations you may have about your child's ability to communicate? IF NO FOR ALL Q. 6A-6E, GO TO Q. 7 IF YES TO ANY Q. 6A-6E, CONTINUE Did you get any advice or plans for next steps? Yes	c concerns or physical abilities or	1	2 (GO	7 TO Q. 6h)	8	
	e. Have you fill out a questionnaire about specific observations you may have about your child's ability to communicate? IF NO FOR ALL Q. 6A-6E, GO TO Q. 7 IF YES TO ANY Q. 6A-6E, CONTINUE Did you get any advice or plans for next steps? Yes	c concerns or physical abilities or	1	2 (GO - (GO -	7 ГО Q. 6h) ГО Q. 6h)	8	5
	e. Have you fill out a questionnaire about specific observations you may have about your child's ability to communicate? IF NO FOR ALL Q. 6A-6E, GO TO Q. 7 IF YES TO ANY Q. 6A-6E, CONTINUE Did you get any advice or plans for next steps? Yes	c concerns or physical abilities or physical abilities or ow	1	2 (GO · (GO ·	7 ГО Q. 6h) ГО Q. 6h)	8	8
	e. Have you fill out a questionnaire about specific observations you may have about your child's ability to communicate? IF NO FOR ALL Q. 6A-6E, GO TO Q. 7 IF YES TO ANY Q. 6A-6E, CONTINUE Did you get any advice or plans for next steps? Yes	c concerns or physical abilities or physical abilities or ow	1	2 (GO (GO	7 ГО Q. 6h) ГО Q. 6h)	8	8

	Very satisfied,					<i>'</i>
	Satisfied,					2
	Dissatisfied, or					3
	Very dissatisfied?					2
	Refused					7
	Don't know					8
Next	In the past 12 months (18 months for "Targeted sample"), did your child's the following to address [NAME OF CHILD]'s behavioral or mental health regular check-up or well child visit.	s doctor or	other h			
	Did the doctor or other health provider	Yes	No	REF	DK]
	a. Note a concern about your child's behavior or mental health that should be watched carefully?	1	2	7	8	•
	b. Test your child's behavior or mental health?	1	2	7	8	
	c. Refer your child for testing of his/her behavior or mental health?	1	2	7	8	
	d. Have you fill out a questionnaire about specific concerns or observations you may have about how your child interacts with others or your child's behavior?	1	2	7	8	
7e.	Did you get any advice or plans for next steps? Yes No					
	Refused		,	•		
	Don't know					
7f.	Do you feel comfortable with the advice or plans for next steps?					
	Yes					<i>'</i>
	No					2
	Refused					7
	Don't know					8
7g.	How satisfied were you with the way your child's doctor or other health p Would you say	roviders ha	andled t	hese part	ts of the	visit?
	Very satisfied,					1
	Satisfied,					2
	Dissatisfied, or					3
	Very dissatisfied?					2
	Refused					7
	Don't know					8

How satisfied were you with the way your child's doctor or other health providers handled this part of the visit?

6h.

Would you say...

8a.				id <u>you</u> have any issues or concerns about your that you <u>asked</u> about during a visit to the clinic?
		Yes		1
		No		(GO TO Q. 9a)2
			Refused	(GO TO Q. 9a)7
			Don't know	(GO TO Q. 9a)
8b.	How helpful was the doctor or other	er health	care provider in addre	essing your concern or answering your questions?
		Very hel	lpful,	1
		Somewh	nat helpful,	2
		They trie	ed to address, but wer	re not helpful, or3
		They did	d not address the cond	cern4
			Refused	7
			Don't know	8
		Yes	- '	services might also be called "Help Me Grow."1
		No		(GO TO Q. 11a)2
			Refused	(GO TO Q. 11a)7
			Don't know	(GO TO Q. 11a)8
9b.	Did your child's doctor or someone	e from the	e clinic contact Early I	ntervention or Help Me Grow directly for you?
		Yes		(GO TO Q. 9d)
		No		2
			Refused	7
			Don't know	8
9c.	Did your child's doctor or someone contact Early Intervention or Help			nation, like a phone number, so that you could
		Yes		1
		No		2
			Refused	7
			Don't know	8
9d.	Did your child's doctor or other hea			n the clinic do anything else to help you receive the
		Yes (Wh	nat did they do?) 1
		No		2
			Refused	7
			Don't know	8

9e.	Did you bring your child into Ea your home for an assessment?	arly Intervention/Help Me Grow for an assessn ']	nent [AS NEEDED: Or did they co	ome to
		Yes		1
		No		2
		Refused		7
		Don't know		8
9f.	Did your child qualify for any Eashow you're your child had a ne	arly Intervention or Help Me Grow services? [eed for these services?]	AS NEEDED: Did the assessmer	nt
		Yes		1
		No		2
		Refused		7
		Don't know		8
9g.		y Intervention or Help Me Grow services? Exa tal health and other services that the school d		
		Yes,		1
		No, or	(GO TO Q. 9i)	2
		Not yet, but will in the near future?	(GO TO Q. 9j)	3
		Refused	(GO TO Q. 9j)	7
		Don't know	(GO TO Q. 9j)	8
9h.	How helpful have these service	es been for your child or family? Would you sa	av	
0	Tion Tionplai Tiavo Gioco col Vice	Very helpful,		1
		Somewhat helpful, or		
		Not helpful?		
		Refused		
		Don't know	` ,	
9i.	Is there anything keeping your these services?	child from getting these services or any reaso	n you would prefer your child not	to get
9j.	Did your child's doctor or other getting Early Intervention service	health providers follow-up with you after the coes?	linic visit to find out if your child w	/as
		Yes		1
		No		2
		Refused		7
		Don't know		0

Please tell me whether you agree or disagree with the following statements about the referral to Early Intervention services.

		Would you say					
		Strongly disagree,	Disagree,	Agree, or	Strongly agree?	REF	DK
a.	The reasons why my child was referred to Early Intervention were explained to me.	1	2	4	5	7	8
b.	I have a right to approve all Early Intervention services my child receives	1	2	4	5	7	8
C.	My questions about the referral were answered in a timely manner	1	2	4	5	7	8
d.	I feel this was an appropriate referral for my child	1	2	4	5	7	8

11a.	During the past 12 months(18 months for "Targeted sample"), did your child's doctor or other health providers at the
	clinic refer you to a specialist (for example, occupational or physical therapy, speech therapy, Orthopedics,
	Audiology or mental health clinic)?

Yes			1
No		(GO TO Q. 13a)	2
	Refused	(GO TO Q. 13a)	7
	Don't know	(GO TO Q. 13a)	8

11b.	What types of specialists were you referred to?	

11c. Did your child's doctor or someone from the clinic contact the specialty directly for you?

Yes		(GO TO Q. 11e)	. 1
No			. 2
	Refused		. 7
	Don't know		0

11d. Did your child's doctor or someone from the clinic give you information, like a phone number, so that you could contact a specialist?

Yes		1
No		2
	Refused	7
	Don't know	8

Did someone from the clinic help you or your child in any other ways to receive the care from the specialist? 11e.

Yes (What did they do?) 1
No	2
Refused	7
Don't know	8

11f.	Did your child go to the specialist? Yes,		1
	No, or	(GO TO Q. 11h)	2
	Not yet, but will in the near future?	(GO TO Q. 11i)	3
	Refused	(GO TO Q. 11i)	7
	Don't know	(GO TO Q. 11i)	8
11g.	How helpful was the specialist? Would you say		
	Very helpful,	(GO TO Q. 11i)	1
	Somewhat helpful, or	(GO TO Q. 11i)	2
	Not helpful?	(GO TO Q. 11i)	3
	Refused	(GO TO Q. 11i)	7
	Don't know	(GO TO Q. 11i)	8
11h.	Is there anything keeping your child from getting these services or any reas child not to get these services?	son you would prefer your	
11i.	Did your child's doctor or other health providers follow-up with you to ask if about the visit?	your child visited the specialist or a	ask
	Yes		1
	No		2
	Refused		7

12. Please tell me whether you agree or disagree with the following statements about the referral to a specialist

		Would you say					
		Strongly disagree,	Disagree,	Agree, or	Strongly agree?	REF	DK
а.	The reasons why my child was referred to a specialist were explained to me.	1	2	4	5	7	8
b.	I have a right to approve all specialist services my child receives.	1	2	4	5	7	8
C.	My questions about the referral were answered in a timely manner.	1	2	4	5	7	8
d.	I feel this was an appropriate referral for my child.	1	2	4	5	7	8

	Yes
	Health, or other community service?
	any other services in the community such as a follow-along program, Home visiting, HeadStart, ECFE, Public
ısa.	During the past 12 months (16 months for Targeted Sample), did your child's doctor of child refer your child for

Yes			1
No		(GO TO Q. 15a)	2
	Refused	(GO TO Q. 15a)	7
	Don't know	(GO TO Q. 15a)	8

13b. What services were you referred to? (LIST UP TO 3 SERVICES)

	NAME OF FIRST SERVICE:	NAME OF SECOND SERVICE:	NAME OF THIRD SERVICE:
Did your child's doctor or someone from the clinic do anything besides the referral to help you receive the services from the community agency?	Yes	Yes	Yes
2. IF YES TO 13b-1. THEN: What was that?			
3. Does/did your child receive these services?	Yes	Yes	Yes

Does your child's primary care provider or these community services?	nurse follow	-up with you	after the	visit to find o	out if your	child wa	as getting
Yes							1
No							2
	Refused						7
	Don't know						8
Please tell me whether you agree or disagre	e with the foll	owing staten	nents abou	ut the referra	I to comm	unity sei	rvices.
	Would you	say					
	Strongly disagree,	Disagree,	Agree, or	Strongly agree?	REF	DK	
	1	2	4	5	7	8	
b. I have a right to approve all community services my child							
	1	2	4	5	7	8	
	1	2	4	5	7	8	
d. I feel this was an appropriate	1				7		
	<u> </u>	_					
sometimes called a "Care Coordinator." Yes	Refused			(GO (GO	TO Q. 15	id)id)	1 2 7
	Don t know		• • • • • • • • • • • • • • • • • • • •	(GO	10 Q. 15	oa)	č
Intervention/Help Me Grow, or community receiving? Would you say Very he	organization	s and stayin	g informe	d about serv	rices you	child is	1
Not help	oful?						3
	Refused						7
	Don't know						8
How satisfied are you with the follow-up th	e Care Coor	dinator does	with you	? Would you	ı say		
Very sa	tisfied,						1
Satisfie	d,						2
Dissatis	fied, or						3
. 3.y u.c							
	these community services? Yes No Please tell me whether you agree or disagree a. The reasons why my child was referred to community services were explained to me. b. I have a right to approve all community services my child receives c. My questions about the referral were answered in a timely manner d. I feel this was an appropriate referral for my child Is there someone at the clinic who coordin your child needs and gathers the informati sometimes called a "Care Coordinator." Yes No Very he Somew Not help How satisfied are you with the follow-up th Very sa Satisfied Dissatis	These community services? Yes	The reasons why my child was referred to community services were explained to me. I have a right to approve all community services were answered in a timely manner to referral for my child needs and gathers the information about your child from sometimes called a "Care Coordinator." Yes	These community services? Yes	Yes	these community services? Yes	Yes

		vices?
	Yes	1
	No	2
	Refused	7
	Don't know	8
How often does your child's own Would you say	doctor or primary provider explain things in a way that you can understa	and?
	Never,	1
	Sometimes,	2
	Usually, or	3
	Always?	4
	Refused	7
	Don't know	8
	NoRefused	7
	ve the way it coordinates service with other medical providers, the school any examples of this type of coordination happening in the past year?	
community. Have you noticed		
Do you have any suggestions	d any examples of this type of coordination happening in the past year?	
Do you have any suggestions	d any examples of this type of coordination happening in the past year?	
Do you have any suggestions services?	d any examples of this type of coordination happening in the past year?	
Do you have any suggestions services?	d any examples of this type of coordination happening in the past year?	

These last questions are just to help us understand more about the people completing this survey. Remember, your answers are confidential and will not be connected to you in any report.

		NIC] do you live?				
	l	ess than 25 miles				
	2	25 to 50 miles				
	Ę	51 to 100				
	ı	More than 100 miles				
		Refused				
		Don't know				
_						
2.	What is your child's racial/ethnic ba	ckground? Is he/she				
			Yes	No	REF	DK
	a. African American		1	2	7	8
	b. American Indian		1	2	7	8
	c. Asian		1	2	7	8
	d. Hispanic/Latino		1	2	7	8
			1	2	7	8
	f. Other (Specify:)	1	2	7	8
	5	Spanish				
	ŀ	•				
		- Hmong				
	,	Hmong/ietnamese				
	\ \$	- Hmong/ietnamese Somali				
	\ \$	Hmong /ietnamese Somali Other (Specify:				
	\ \$					
	\ \$	Hmong /ietnamese Somali Other (Specify:				
4.	\ \$	Hmong Vietnamese Somali Other (Specify: Refused Don't know E. Thanks for taking the time to	be intervie	ewed today	. We really a	appreciate
1.	Those are all of the questions I have help and your time. I have a \$15 Ta	Hmong Vietnamese Somali Other (Specify: Refused Don't know E. Thanks for taking the time to	be intervie	ewed today	. We really a	appreciate
1.	Those are all of the questions I have help and your time. I have a \$15 Takes	Hmong /ietnamese Somali Other (Specify: Refused Don't know e. Thanks for taking the time to arget or Walmart gift certificate to	be intervie	ewed today /ou. Would	. We really a	appreciate
1.	Those are all of the questions I hav help and your time. I have a \$15 Takes	Hmong Jietnamese Somali Ther (Specify: Refused Don't know e. Thanks for taking the time to arget or Walmart gift certificate to A Target Gift Card, or	be intervie	ewed today you. Would	. We really a	appreciate
	Those are all of the questions I hav help and your time. I have a \$15 Takes	Hmong Vietnamese Somali Dther (Specify: Refused Don't know e. Thanks for taking the time to arget or Walmart gift certificate to arget Gift Card, or A Walmart Gift Card Don't want a gift card)	be intervie	ewed today you. Would	. We really a	appreciate
4 .	Those are all of the questions I have help and your time. I have a \$15 To a second with the se	Hmong Vietnamese Somali Dther (Specify: Refused Don't know e. Thanks for taking the time to arget or Walmart gift certificate to arget Gift Card, or A Walmart Gift Card Don't want a gift card)	be intervie to send to y	ewed today you. Would	. We really a	appreciate

26.	What is your correct address?
27.	Your gift certificate will be sent by certified mail within the next week or two. This means that the mail carrier will bring it to your door for a signature, to ensure that it isn't lost or stolen. INTERVIEWER; IF CERTIFIED MAIL IS A PROBLEM, GIVE R A CHOICE OF HAVING IT SENT ELSEWHERE OR HAVING IT SENT BY REGULAR MAIL A HER OWN RISK. THIS MEANS THAT IF THEY DON'T RECEIVE IT, WE WILL NOT REPLACE IT.
	Certified
	Regular mail
Inter	viewer: Date: viewer Employee #:
If inte	erview was completed in language, other than English, please list language:
If co	mpleted in English, please rate the respondent's fluency in English:
	Excellent
	Very good
	Good
	Fair
	Poor