



# ABCD III: Results of parent interviews

*Baseline family feedback about experiences at participating clinics*

MARCH 2011

# ABCD III: Results of parent interviews

## *Baseline family feedback about experiences at participating clinics*

Supported by The Commonwealth Fund, a national, private foundation based in New York City that supports independent research on health and social issues. The views presented here are those of the author and not necessarily those of The Commonwealth, it's directors, officers, or staff.

**March 2011**

**Prepared by:**

Krysten Lynn Ryba and Michelle Decker Gerrard

Wilder Research  
451 Lexington Parkway North  
Saint Paul, Minnesota 55104  
651-280-2700

[www.wilderresearch.org](http://www.wilderresearch.org)

# Contents

Executive summary.....	1
Background.....	4
ABCD III objectives and related research questions .....	6
Research methods .....	7
Summary of demographic characteristics.....	9
Baseline interview results .....	10
Respondents’ background experiences with participating clinics .....	10
Screening and assessment.....	10
Referrals to specialists, community services, and Early Intervention .....	14
Issues to consider .....	22
Appendix.....	23
Data tables.....	25
Interview instrument .....	30

# Figures

1. Response rates by clinic.....	9
2. In the past 12 months, did your child’s doctor or other health provider do any of the following to address learning or development?.....	11
3. Other perceptions of parents whose child received some learning or developmental screening, assessment, or referrals for testing.....	11
4. In the past 12 months, did your child’s doctor or other health provider do any of the following to address behavior or mental health?.....	12
5. Other perceptions of parents whose child received some type of mental health screening, assessment, or referrals for testing .....	12
6. Screening, assessment, and noted concerns, by age .....	13
7. Type of referrals and services received in past 12 months .....	14
8. Types of referrals, by site.....	15
9. Types of referrals, by age.....	15
10. Assistance with referrals to specialists in the past 12 months .....	16
11. Perceptions of child’s referral to a specialist .....	17
12. Assistance with referrals to community services (other than Help Me Grow) in the past 12 months .....	17
13. Perceptions of child’s referral to community services.....	18
14. Assistance with referrals to Early Intervention in the past 12 months .....	19
15. Perceptions of child’s referral to Early Intervention/Help Me Grow .....	19
16. Care coordination services .....	20
17. Other linkages to resources through primary care clinics.....	21

# Acknowledgments

Wilder Research would like to thank staff from the Minnesota Department of Human Services for their assistance with instrument and data collection design for this evaluation. In particular, we would like to thank Susan Castellano, Ruth Danielzuk, Glenace Edwall, Meredith Martinez, and Virginia Zawistowski. We would also like to thank staff at the participating clinics for their assistance in identifying families eligible for the study.

Wilder Research staff who contributed to this project include:

Jackie Campeau  
Phil Cooper  
Paul Dalton  
Janell Felker  
Melanie Ferris  
Louann Graham  
Rachel Hardeman  
Cheryl Holm-Hansen  
Cassandra Johnson  
Muneer Karcher-Ramos  
Zeinab Khalif  
Margaree Levy  
Miguel Salazar  
Shelley Slominski  
Abigail Struck  
Dan Swanson  
Lue Thao

Finally, we would like to thank the parents who participated in this study for their helpful insights and valuable feedback.

# Executive summary

## *Project background*

The Assuring Better Child Health and Development (ABCD) III initiative is supported through a three-year grant from the National Academy for State Health Policy, administering the grant for The Commonwealth Fund to the Minnesota Department of Human Services (DHS), awarded in 2009. The purpose of the initiative is to develop and test sustainable models for improving care coordination, referrals, and feedback between pediatric primary care, and child and family service providers offering developmental and mental health services to children ages birth to 5 years as well as other medical providers. The goal is to support four pilot sites (in Anoka, Olmsted, Ramsey, and Saint Louis counties) in developing a system that assures efficient linkages between primary care, community-based Early Intervention/Help Me Grow programs, and other medical providers.

This report summarizes the results of telephone interviews conducted with 95 parents of young children served at primary care clinics involved with the initiative. Interviews were conducted between October 2010 and January 2011. These interviews were conducted to learn about parent perceptions of the participating clinics' screening, referral, communication, and coordination practices at the start of the ABCD III initiative. Parent interviews will be repeated annually in 2011 and 2012 to identify changes in referral patterns, communication, and coordination that result from the primary care teams' participation in this initiative.

## *Baseline status*

Most families interviewed have longstanding relationships with their clinic and regular health providers and take their child for well-visits consistently. In addition, comments suggest that families are satisfied with the services they receive.

It is important to note that these interviews were designed and conducted as baseline assessments of parents' perceptions. It is anticipated that some of the following baseline interview results may change as systemic improvements are made:

**Most children received some type of screening or assessment and parents felt satisfied with the process.** The majority of parents reported that they had completed a questionnaire related to their child's development (63%) and mental health (56%) at the participating clinic in the past year. Parents were highly satisfied with the way health providers handled developmental and mental health screening and assessment aspects of the visit. However, only half of parents whose child received a mental health assessment

*discussed next steps with their provider*, compared to 62 percent of those whose child received a developmental assessment.

**In the vast majority of cases, the health provider noted no concerns related to the child's development or mental health.** Only 15 percent of families said that they had a child with a developmental concern, and 6 percent had a child with a mental health concern, that their health provider noted should be watched carefully. In the past year, most families (72%) had not been referred by their primary care clinic to specialists, Early Intervention, or other community services.

**Fewer than half of respondents whose health provider noted a developmental or mental health concern were referred to Early Intervention/Help Me Grow.** Of those respondents who said that their health provider noted a concern about their child's development (N=14), 43 percent (or 6 children) said they received a referral to Early Intervention/Help Me Grow. Of those who said that their health provider noted a concern about their child's mental health (N=6), one child received a referral to Early Intervention/Help Me Grow.

**Referrals occur most often for specialists (18%), with few referrals made for various community services (10%) or Early Intervention/Help Me Grow (7%).** Of the parents who reported receiving a referral, the child more often received services in the case of specialists (88%) and community services (78%). Just four of seven families referred to Early Intervention/Help Me Grow (57%) were assessed and received services.

**Children who were age 3 to 5 were referred to specialists, community services, and Early Intervention/Help Me Grow at higher rates than children younger than 3.** Parents of children age 3 to 5 reported that they were referred to Early Intervention/Help Me Grow at more than twice the rate of children younger than 3 (13% versus 6%). Similarly, 19 percent of parents of children age 3 to 5 reported that they were referred to other community services (compared to 8% of those who had a child younger than 3).

**There were variations among the sites in the rates of screening and referral.** Parents reported variation in several areas such as the rate of mental health screening and assessment which ranged, by site, from 44 to 77 percent. Parents from primarily one clinic reported referrals for Early Intervention/Help Me Grow services. As follow-up interviews occur, it will be important to analyze results by clinic to measure changes that occur for each participating team over time.

## *Other considerations*

Because this is a baseline interview conducted in the early stages of the initiative, the number of referrals is expected to increase in years two and three – especially referrals for Early Intervention/Help Me Grow and other community services. Given the small numbers of referrals made, it is important to interpret data related to baseline perceptions and satisfaction with caution.

In addition, it is difficult to discern if parents fully understood the questions related to screening. Some of the patterns in interview responses show that parents more frequently responded that they completed questionnaires related to various aspects of their child’s development or mental health, and less frequently were “tested” by the health provider. Therefore, it may be useful to review these questions further before the follow-up interviews are conducted.

Finally, the parent interview is part of a larger set of data collection activities used to understand the baseline status and subsequent progress of the ABCD III initiative. At follow-up, it will be useful to examine these results in conjunction with other data sources to fully understand progress toward the initiative’s objectives.



# Background

The Assuring Better Child Health and Development (ABCD) III initiative is supported through a three year grant from the Board of the Commonwealth Fund to the Minnesota Department of Human Services (DHS), awarded in 2009. The purpose of the initiative is to develop and test sustainable models for improving referrals and care coordination and feedback between pediatric primary care, and child and family service providers offering developmental and mental health services to children ages birth to 5 years as well as other medical providers. The goal is to support four pilot sites (in Anoka, Olmsted, Ramsey, and Saint Louis Counties) in developing a system that assures efficient linkages between primary care, and community-based Early Intervention/Help Me Grow programs, and other medical providers. A variety of strategies will be used to enhance care coordination, including establishing or strengthening linkages between primary care clinics, community-based medical specialists, and Early Intervention/Help Me Grow programs. If successful, the initiative will result in benefits such as increased rates of referral, timely access to services for children with potential developmental and/or social-emotional concerns, and improved feedback and coordination among service providers.

Wilder Research has been contracted to evaluate the initiative. This report describes findings of baseline interviews conducted with families. Wilder Research worked closely with DHS to develop a survey tool focused on understanding 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. These parent interviews will be repeated annually to identify changes in referral patterns, communication, and coordination that result from participation in this initiative.

## **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.

- Help Me Grow eligibility is based on certain diagnosed physical or mental conditions or disorders, demonstrated delays as measured by assessment and evaluation procedures in cognitive, physical, communication, social or emotional and adaptive development areas

and/or a high probability of a delay resulting from a physical or mental condition, regardless of whether the child is currently demonstrating a need or delay.

- Once referred to Help Me Grow, a family will be contacted by staff from their local community to get more information regarding the concerns. Members of a team of trained early childhood specialists will arrange for a developmental screening or schedule a comprehensive evaluation to determine eligibility for Help Me Grow: Infant and Toddler Intervention Services or Preschool Special Education Services.
- An Individualized Family Services Plan (IFSP) for ages 0-2 or an Individualized Education Program (IEP) for ages 3-5 is created for children who meet the program requirements. This written plan provides a clear outline of priorities, services, and outcomes for early intervention services and preschool special education services.
- A service coordinator is assigned to help families of children ages 0-2 access services and resources, convene IFSP meetings and periodic reviews, and change the service plan as needed. Children ages 3-5 receiving services through an IEP will be assigned as IEP Case Manager.

### **About the pilot teams**

Four pilot teams located in Anoka, Olmsted, Ramsey and Saint Louis counties were selected to participate in the ABCD III initiative.

- **Anoka County:** Fridley Children’s and Teenagers’ Medical Clinic and community partners – Fridley, Minnesota and North Metro Pediatrics and community partners – Coon Rapids, Minnesota
- **Olmsted County:** Mayo Pediatrics and community partners – Rochester, Minnesota
- **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.
- **Ramsey County:** East Side Family Clinic and community partners – Saint Paul, Minnesota. This clinic discontinued its participation in ABCD III in late 2010. However, during the period that the East Side Family Clinic participated, eight families completed baseline interviews. These baseline results are included in the overall baseline results for this study. A new clinic joined the Ramsey County team in early 2011. This team now includes HealthPartners White Bear Lake Clinic and

community partners. Results of interviews with HealthPartners White Bear Lake Clinic families will be included in subsequent reports.

### ***ABCD III objectives and related research questions***

This report is focused on the first of three interviews with families to be conducted over the course of the study. Four objectives were identified as part of this initiative. Evaluation of progress toward each objective is measured through several data sources, including parent feedback. For each of the four objectives, evaluators identified research questions that would be addressed through the parent interview:

**Objective 1:** Early intervention services in the pilot communities will receive increased referrals of children (closer to the expected rate) and the referrals will be earlier (based on child's age) than had previously occurred.

- To what extent do children and families receive an appropriate and timely array of assessments and services? (measures 1.3, 1.4 from the *Minnesota ABCD III Objectives and Draft Evaluation Measures* submitted by the Department of Human Services in March 2010)
- How many of the children referred qualified for services? What kind of services did they receive? (measure 1.5)

**Objective 2:** Clinics will know when to refer children based on screening results and to whom children should be referred. Each community agency and clinic will have a good working relationship with the other. Necessary information will flow well between primary care providers and community agencies and service providers. Providers will feel more comfortable with referrals made and know what happened as a result.

- To what extent do clinics and community programs work together to coordinate care for the child/family? (measure 2.9b)

**Objective 3:** Participating clinics will have a systematic process in place for screening, referring, and managing services for young patients and their families that will include communication between providers and the family. Pilot communities will have standard communication mechanisms in place to provide timely referrals and feedback between clinics and providers and agencies where children are referred.

This objective is being evaluated using other data sources. However, data from the follow-up parent interviews may give a helpful parent perspective that will inform better understanding of progress toward this objective.

**Objective 4:** Families will experience more coordinated care, feel more comfortable about referrals, diagnosis, or lack thereof, and usefulness of anticipatory guidance given and comprehensiveness of well-child visit will improve.

- To what extent do families feel comfortable with referrals and/or diagnosis or lack thereof? (measure 4.1a)
- To what extent are families satisfied with the developmental and mental health aspects of the visit, the comprehensiveness of the well-visit, and the usefulness of anticipatory guidance given? (measures 4.1b-4.1d)

## ***Research methods***

In August and September 2010, Wilder Research collaborated with the Minnesota Department of Human Services to design the parent interview protocol with questions based around the care received for a selected child. Based on these discussions, the following criteria were used to select the participant sample.

### **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. Other criteria for inclusion in the study include:

- Child enrolled in a Minnesota Health Care Plan
- Child (age 0-5) screened within the past year
- Child received well-child visit in the past 3 months
- Current contact information available

Because this was a baseline sample, children were eligible if they received services from any primary care provider of pediatric services, even if the provider was not involved with the initiative.

Based on these criteria, each of the five clinics generated a list of eligible families. The Mayo Pediatrics sample list included slightly younger children on average. This is because their model includes mailed screening to children at defined intervals (one occurs at the child's 18 month birthday). Other clinics include screening as part of the well-child visit, and thus may have more variation in the age of children included in the study.

Wilder Research staff excluded from the sample those families whose eligibility was based on a child under 12 months old for two reasons. First, some questions asked parents 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.

Wilder Research staff randomly selected from each clinic's list to achieve the targeted sample size of 50 cases per clinic. In cases in which more than one child per family was sampled, one child was randomly selected. Because North Metro Pediatrics is a small practice, all eligible families (N=11) were selected.

Before the telephone interviews were conducted, 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 participate or withdraw from the study.

### **Additional information about interviews conducted**

Between October 2010 and January 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 received a \$15 gift card to Target or Wal-Mart to thank them for their time. A copy of the interview guide is included in the Appendix.

In all, 95 parents completed interviews. Eight of these interviews were conducted with parents whose children received care from the East Side Family Clinic. As noted previously, East Side Family Clinic is no longer participating in ABCD III and has been replaced by HealthPartners White Bear Lake Clinic. However, the eight interviews are included in the overall baseline results for this study. Subsequent interviews completed in 2011 and 2012 will include families from HealthPartners White Bear Lake Clinic.

---

## 1. Response rates by clinic

	Sample size	Number interviewed	Response rate
Saint Luke's Pediatric Associates, St. Louis County	50	31	62%
Fridley Children's and Teenagers' Medical Clinic and North Metro Pediatrics, Anoka County	61	32	52%
Mayo Pediatrics, Olmsted County	50	24	48%
<b>Total</b>	<b>161</b>	<b>87</b>	<b>54%</b>
<i>East Side Family Clinic, Ramsey County</i>	<i>50*</i>	<i>8</i>	<i>NA</i>

\* *East Side Family Clinic discontinued participation while the parent interviews were in the field. Eight interviews were completed before East Side Family Clinic discontinued. These interviews are included, because of the baseline nature of this study. However, they are not included in the sample size or response rate.*

Wilder Research interviewers were unable to locate 46 respondents. In addition, 11 respondents refused the interview, 8 respondents were unavailable after 10-15 attempts to reach them, and 9 respondents had other barriers to participation, including language issues.

### **Presentation of data tables**

Throughout this report, responses from Fridley Children's and Teenagers' Medical Center and North Metro Pediatrics are reported as one site. Due to their withdrawal from the initiative, East Side Family Clinic responses are included only in the total column of each table.

### ***Summary of demographic characteristics***

All respondents had children between the ages of 1 and 5, as defined by the study criteria. Two-thirds of the children (66%) were 19 months to 3 years old. There was little variation among sites in terms of the age distribution of the focal child. However, children who received care at Mayo Pediatrics were under 3 years old, because of the timing of their screening procedures (described previously).

Respondents' children came from a variety of backgrounds; over half (57%) were White. Seventeen percent were Hispanic/Latino, 12 percent identified their children as two or more races, 9 percent were African American, and 2 percent were Asian.

English was the primary language spoken at home for 82 percent of respondents. Thirteen percent spoke Spanish, and 5 percent specified other languages, including Somali and Arabic. Interviews were conducted in both English (N=88) and Spanish (N=7).

Additional information about demographic characteristics is included in the Appendix.

# Baseline 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.

- Overall, 97 percent of respondents said the clinic they last visited was the place their child usually receives care.
- The majority (89%) of those interviewed indicated their child had a regular doctor or health provider at the clinic. Of those, 73 percent had seen their regular provider on their child's last visit to the clinic.
- Respondents often had long-term relationships with their clinic, with 88 percent reporting their child had been using the clinic for more than one year.
- More than half of families interviewed (55%) had visited the clinic four or more times in the past year.

Additional information about respondents' relationship with the participating clinics is included in the Appendix.

## *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.

- 83 percent of parents reported that their child received some type of developmental screening, assessment, or referral by their health provider in the past year (Figure 2).
- Parents were most likely to say that their provider had them complete a questionnaire about specific physical or communication concerns (63%) (Figure 2).

**2. In the past 12 months, did your child’s doctor or other health provider do any of the following to address learning or development?**

	Percent YES			
	Mayo Pediatrics (N=24)	Saint Luke’s Pediatric Assoc. (N=31)	Fridley and North Metro (N=32)	Total (N=95)
Have you complete a questionnaire about specific concerns you may have about your child’s physical abilities or ability to communicate	75%	71%	45%	63%
Test your child’s learning or development	35%	55%	56%	51%
Note a concern about your child’s learning or development to be watched carefully	4%	16%	19%	15%
Refer your child for speech-language or hearing testing	8%	13%	13%	11%
Refer your child for testing of his/her learning or development	4%	7%	13%	9%
<b>At least one of the above</b>	<b>83%</b>	<b>87%</b>	<b>78%</b>	<b>83%</b>

In addition, of those who received advice or next steps about aspects related to their child’s learning and development (N=49), almost all (98%) were comfortable with the information from their child’s health provider.

**3. Other perceptions of parents whose child received some learning or developmental screening, assessment, or referrals for testing**

	Mayo Pediatrics (N=20)	Saint Luke’s Pediatric Assoc. (N=27)	Fridley and North Metro (N=25)	Total (N=79)*
Received advice or plans for next steps from clinic doctor or staff	55%	67%	64%	62%
“Very satisfied” with the way child’s doctor handled this part of visit	80%	78%	72%	79%

\* Asked only of those who received some type of screening or assessment in this area.

**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.

- 61 percent of parents reported that their child received some type of behavioral or mental health screening, assessment, or referral in the past year. There was variation in the rate of mental-related screening, assessment, and referral among the clinics.



- Overall, fewer respondents’ reported that the health provided *tested* their child for behavior or mental health (18%) versus those whose child was tested for learning or development (51%).
- Similar to the developmental assessment, most parents said they had completed a questionnaire about their concerns regarding their child’s behavior or mental health (56%).

**4. In the past 12 months, did your child’s doctor or other health provider do any of the following to address behavior or mental health?**

	Mayo Pediatrics (N=24)	Saint Luke’s Pediatric Assoc. (N=31)	Fridley and North Metro (N=32)	Total (N=95)
Have you complete a questionnaire about specific concerns you may have about how your child interacts with others or their behavior	67%	77%	31%	56%
Test your child’s behavior or mental health	8%	23%	19%	18%
Note a concern about your child’s behavior or mental health to be watched carefully	4%	7%	3%	6%
Refer your child for testing of his/her behavior or mental health	4%	7%	-	3%
<b>At least one of the above</b>	<b>67%</b>	<b>77%</b>	<b>44%</b>	<b>61%</b>

Satisfaction ratings with the way the primary care provider handled behavioral or mental health assessments are high. However, only half of parents who reported that their child received a mental health assessment said they received advice about next steps.

Of those who received advice or next steps about their child’s behavior or mental health assessments (N=29), all were comfortable with the information from their child’s health provider.

**5. Other perceptions of parents whose child received some type of mental health screening, assessment, or referrals for testing**

	Mayo Pediatrics (N=16)	Saint Luke’s Pediatric Assoc. (N=24)	Fridley and North Metro (N=14)	Total (N=58)*
Received advice or plans for next steps from clinic doctor or staff	38%	58%	50%	50%
“Very satisfied” with the way child’s doctor handled this part of visit	81%	67%	64%	71%

\* Asked only of those who received some type of screening or assessment in this area.

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

There was variation in the rate of some screening and assessment activities, by age grouping. Parents of older children, ages 3 to 5, less frequently reported that they were asked to complete questionnaires regarding their child’s development and mental health. Conversely, parents of older children, ages 3 to 5, more frequently reported that their child had been tested by their health provider for development and mental health (Figure 6).

### 6. Screening, assessment, noted concerns, by age

	Under age 3 (N=79)	Ages 3-5 (N=16)	Total (N=95)
Parent completed a questionnaire about concerns regarding child’s physical abilities or ability to communicate	70%	27%	63%
Test your child’s learning or development	50%	60%	51%
Provider noted a concern about child’s learning or development to be watched carefully	14%	19%	15%
Parent completed a questionnaire about concerns regarding how child interacts with others or their behavior	60%	38%	56%
Test your child’s behavior or mental health	4%	19%	6%
Provider noted a concern about child’s behavior or mental health to be watched carefully	18%	20%	18%

### Other developmental or mental health concerns identified by parents

Twenty-nine percent reported that they asked about an issue concerning their child’s growth, development, learning, behavior, or mental health during the past 12 months. Many parents (74%) found the information they received in response to their concerns “very helpful,” 15 percent found it “somewhat helpful,” and 11 percent responded that the health provider “tried to address the concerns but was not helpful.” No parents responded that the provider did not address the concerns.

No parents reported having any issues or concerns that they did not ask their child’s health provider about during the visit to the clinic.

## ***Referrals to specialists, community services, and Early Intervention***

The ABCD III initiative seeks to develop and improve linkages between pediatric primary care, other medical providers/specialists, and community services offering developmental and mental health services to children ages birth to 5 years.

Because this baseline interview was conducted in the early stages of the initiative, the number of referrals is expected to increase in years two and three – especially referrals for community services and Early Intervention/Help Me Grow. Given the small numbers of referrals made in the respective categories, it is important to interpret data related to perceptions and satisfaction with caution.

- Specialists and community services currently have the greatest uptake, meaning families referred to these providers for services received them at a higher rate.

---

### **7. Type of referrals and services received in past 12 months**

	Received Referral		Received Services	
	Number	Percent	Number	Percent
Specialist	17	18%	15	88%
Early Intervention/Help Me Grow	7	7%	4	57%
Other community services	9	10%	7	78%
<i>More than one type of referral</i>	4	4%	4	100%

**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/Help Me Grow), one received a referral to Help Me Grow and a specialist, and another was referred to community services and a specialist

### **Description of community services received**

As part of this initiative, in addition to referring children who needed further assessment to Help Me Grow, clinics and pediatric health providers are encouraged to refer families to community services focused on child development. Those mentioned by parents responding to the baseline interview include:

- **Follow Along Program (FAP):** The FAP is a partnership between state and local public health agencies offered to families as a way to track the development of their children and to learn about normal growth and development. (N=2)

- Early Childhood Family Education (ECFE): ECFE is a program offered through Minnesota Public Schools for all families with children between the ages of birth to kindergarten entrance. ECFE’s goal is to enhance the ability of all parents to provide the best possible environment for their children’s learning and growth. (N=3)
- Head Start and Early Head Start: These programs provide comprehensive services – education, parent involvement, health, nutrition, and social – all of which are coordinated with community-based service systems. (N=2).

### **Variations in referrals by site**

There was variation in the rate of referrals to specialists, community services, and Early Intervention by site. For instance, five of the seven families referred to the Early Intervention/Help Me Grow program received services from Fridley Children’s Medical Clinic or North Metro Pediatrics.

---

#### **8. Types of referrals, by site**

	<b>Mayo Pediatrics (N=24)</b>	<b>Saint Luke’s Pediatric Assoc. (N=31)</b>	<b>Fridley and North Metro (N=32)</b>	<b>Total (N=95)</b>
Specialist	12%	23%	22%	18%
Community Services	-	13%	10%	10%
Early Intervention/Help Me Grow	-	7%	16%	7%

### **Variations in referrals by age**

There was variation in the rate of referrals to specialists, Early Intervention, and community services by age groupings; older children, ages 3 to 5, were referred at higher rates. For 3 to 5 year olds, rates of referral to Early Intervention/Help Me Grow and community services were more than twice that of those children younger than age 3.

---

#### **9. Types of referrals, by age**

	<b>Under age 3 (N=79)</b>	<b>Ages 3-5 (N=16)</b>	<b>Total (N=95)</b>
Referred to specialist	17%	25%	18%
Referred to Early Intervention/Help Me Grow	6%	13%	7%
Referred to other community Services	8%	19%	10%

## Respondents' experience with referrals to specialists

In the previous 12 months, 17 respondents received a referral from their child's health provider to see a specialist. The specialists included: orthopedics; audiologists; ear, nose and throat physicians; mental health providers; pulmonologists; allergists; and pediatric developmental specialists.

When they are referred, most parents (88%) report that clinics and health providers provided the specialist's information, such as a phone number, to assist parents in scheduling appointments. Forty-one percent of parents report that clinics and health providers scheduled the appointment directly on the parent's behalf. Over half of parents (58%) reported that clinic doctors and staff asked about or followed-up with families regarding the appointment with the specialist. Additionally, 10 of the 15 respondents who were referred to a specialist and received services reported that their primary care provider subsequently asked them about their visit to the specialist.

### 10. Assistance with referrals to specialists in the past 12 months

	Mayo Pediatrics (N=3)	Saint Luke's Pediatric Assoc. (N=7)	Fridley and North Metro (N=7)	Total (N=17)
Clinic doctor or staff provided specialist information, like a phone number	100%	71%	100%	88%
Clinic scheduled appointment directly*	33%	57%	28%	41%
Clinic doctor or staff asked about appointment with specialist/followed-up *	50%	67%	83%	58%

\* Of those receiving a referral to a specialist (N=17) 15 had received those services at the time of the interview, and 2 planned to receive specialist services in the near future.

**Note:** Respondents could give more than one response.

### Rates of referrals for clients who may have received a “positive” screening

- Of those parents whose clinic doctor or health provider noted a concern about their child's learning or development (N=14), 43 percent (or 6 children) received a referral to a specialist.
- Three of the six respondents (50%) whose clinic doctor or health provider noted a concern about their child's behavior or mental health received a referral to a specialist.
- Four parents said that their clinic doctor or health provider noted concerns about their child that should be watched carefully for both learning and development and behavior and mental health; two of them received referrals to a specialist.

## Satisfaction with referral to specialist

Overall, 79 percent of those who were both referred and received services from a specialist (N=15) found the visit and information “very helpful” and another 14 percent said “somewhat helpful.” Only one respondent was dissatisfied with their child’s specialist.

### 11. Perceptions of child’s referral to a specialist

N=17	Strongly disagree	Disagree	Agree	Strongly agree
The reasons why my child was referred to a specialist were explained to me.	12%	-	35%	53%
I have a right to approve all specialist services my child receives.	12%	-	23%	65%
My questions about the referral were answered in a timely manner.	12%	-	47%	41%
I feel this was an appropriate referral for my child.	12%	-	25%	63%

Respondents who visited Saint Luke’s Pediatric Associates for their child’s care and received a referral to a specialist (N=7) were more likely than those served by other clinics to “strongly agree” that reasons for the referral were explained to them (71%), that they have a right to approve the specialist services their child receives (71%), and that the referral was appropriate for their child (71%).

### Respondents’ experience with community service referrals

Of the 95 respondents interviewed, nine received referrals to community services, and seven children had received those services. Two children were receiving multiple community services.

Figure 12 shows parent ratings of the assistance and follow-up provided related to the community service referral.

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

	Mayo Pediatrics (N=0)	Saint Luke’s Pediatric Assoc. (N=4)	Fridley and North Metro (N=3)	Total (N=9)
Clinic doctor or staff helped you receive services from community agencies beyond the referral	-	75%	33%	44%
Clinic doctor or staff asked about community services received/followed-up*	-	75%	33%	56%

\* Of those receiving a referral to community services (N=9) 7 had received those services at the time of the interview, and 1 planned to receive specialist services in the near future.

When asked how their child’s clinic doctor or health provider helped them to receive community services (besides the referral), respondents specified the provider had provided information, put together needed medical records, and/or conducted an assessment or screening.

Compared to measures asked about referrals to specialists, respondents had similar levels of agreement related to the way the community referral and questions regarding if it was explained to them. Respondents were slightly less likely to agree that the community referral was appropriate for their child. However, given the small number of families represented by these respective referrals, data should be interpreted with caution.

---

### 13. Perceptions of child’s referral to community services

N=9	Strongly disagree	Disagree	Agree	Strongly agree
The reasons why my child was referred to the community services were explained to me.	-	11%	33%	56%
I have a right to approve all community services my child receives.	-	11%	11%	78%
My questions about the referral were answered in a timely manner.	-	11%	44%	44%
I feel this was an appropriate referral for my child.	-	22%	22%	56%

### Respondents’ experience with Early Intervention/Help Me Grow referrals

In addition to child and family community services, of particular interest to DHS is increasing linkages between primary care clinics and Early Intervention services like Help Me Grow: Infant and Toddler Intervention or Preschool Special Education offered through Minnesota Public Schools.

Seven respondents (7%) said their child’s clinic doctor or health provider referred them to Early Intervention/Help Me Grow; of those respondents, four (4%) brought their children in for the assessment and are currently receiving services through the program.

- All of those who were referred and received services from Early Intervention/Help Me Grow (N=4) found services “very helpful.”
- Of the three families who received a referral to Early Intervention/Help Me Grow but have not received services, two said there was no particular reasons they have not acted on the referral, and one offered “I don't think [child] really needed it so that's why we didn't go.”

Fewer than half of respondents whose health provider noted a developmental or mental health concern were referred to Early Intervention/Help Me Grow. Of those respondents who said that their health provider noted a concern about their child’s development (N=14), 43 percent (or 6 children) said they received a referral to Early Intervention/Help Me Grow. Of those who said that their health provider noted a concern about their child’s mental health (N=6), one child received a referral to Early Intervention/Help Me Grow.

Figure 14 shows parent ratings of the assistance and follow-up provided related to the Early Intervention/Help Me Grow referral.

#### 14. Assistance with referrals to Early Intervention in the past 12 months

	Mayo Pediatrics (N=0)	Saint Luke’s Pediatric Assoc. (N=2)	Fridley and North Metro (N=5)	Total (N=7)
Clinic doctor or staff did something to assist in referral beyond giving Early Intervention/Help Me Grow contact information	-	50%	80%	71%
Clinic doctor or staff asked about receiving Early Intervention/Help Me Grow services*	-	50%	50%	50%

\* Of those receiving a referral to Early Intervention/Help Me Grow (N=7) 4 had received those services at the time of the interview.

Compared to their ratings of the referrals to specialists and community services, respondents are less likely to “strongly agree” that they understand why they received the referral, their rights concerning services, that they had their questions answered, and felt the referral was appropriate.

#### 15. Perceptions of child’s referral to Early Intervention/Help Me Grow

N=7	Strongly disagree	Disagree	Agree	Strongly agree
The reasons why my child was referred to Early Intervention were explained to me.	-	-	57%	43%
I have a right to approve all Early Intervention services my child receives.	-	-	71%	29%
My questions about the referral were answered in a timely manner.	-	-	71%	29%
I feel this was an appropriate referral for my child.	-	-	71%	29%



## Respondents' experience with Care Coordinators

The ABCD III initiative also seeks 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. At baseline, 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, 13 percent responded that they are currently receiving care coordination services through their clinic.

- Most respondents (93%) said they did not feel they needed someone to coordinate their child’s care.
- Families receiving care coordination (N=11) found it “very helpful” (70%) or “somewhat helpful” (30%) and were “very satisfied” (70%) or “satisfied” with the follow-up the care coordinator provides for them.
- Of those who said they would like this type of assistance (N=7), four were receiving care coordination services at the time of the interview.
- Respondents whose health provider noted a developmental concern that should be watched carefully were more likely to receive care coordination (29% versus 10% of those who did not have a concern). The difference is smaller for those whose provider noted a behavior or mental health concern (17% versus 13% of those who did not have a concern).
- Two of the four families receiving Early Intervention/Help Me Grow services were also receiving care coordination.

---

### 16. Care coordination services

	Mayo Pediatrics (N=24)	Saint Luke’s Pediatric Assoc. (N=31)	Fridley and North Metro (N=32)	Total (N=95)
Currently receiving care coordination through their clinic	8%	10%	19%	12%
Feel they need someone to coordinate care among child’s doctors and services	4%	3%	16%	7%

Finally, parents were asked a few questions about other resources they received through their clinic (Figure 17). Additional comments offered by parents are included in the Appendix.

---

**17. Other linkages to resources through primary care clinics**

	<b>Mayo Pediatrics (N=24)</b>	<b>Saint Luke's Pediatric Assoc. (N=31)</b>	<b>Fridley and North Metro (N=32)</b>	<b>Total (N=95)</b>
Received information from clinic about other public benefits such as Food Stamps, WIC or other resources that may be helpful to you family	50%	58%	48%	52%

# Issues to consider

Through the ABCD III initiative, the Minnesota Department of Human Services seeks to develop and improve linkages between pediatric primary care, other medical providers, and Early Intervention/Help Me Grow for children ages birth to 5 years with the goal of increasing rates of appropriate referrals and timely access to services.

Baseline interviews conducted with 95 parents of children who receive care at participating clinics show that most families interviewed had longstanding relationships with their clinic and regular health providers. In addition, comments suggest families are satisfied with the services they are receiving, including the screening and referrals that they receive.

Baseline study results show that the majority of parents responded that their young child received some type of developmental and mental health screening in the prior year. Rates of developmental screening and follow-up were higher than rates of mental health screening and follow-up. About 1 in 5 families received a referral to a specialist, about 1 in 10 to community services, and 1 in 14 received a referral to Early Intervention. There were variations in the rate of referrals – particularly for Early Intervention/Help Me Grow – by primary care clinic.

Because this is a baseline interview conducted in the early stages of the initiative, the number of referrals is expected to increase in years two and three – especially referrals for community services and Early Intervention/Help Me Grow. Given the small numbers of referrals made, it is important to interpret data related to baseline perceptions and satisfaction with caution.

In addition, it is difficult to discern if parents fully understood the questions related to screening. Some of the patterns in interview responses show that parents more frequently responded that they completed questionnaires related to various aspects of their child's development or mental health, and less frequently were “tested” by the health provider. Therefore, it may be useful to review these questions further before the follow-up interviews are conducted. Over the next few months, Wilder Research and DHS staff intend to examine these questions and their responses closely to ensure that they are as clear as possible.

Finally, the parent interviews are part of a larger set of data collection activities used to understand the baseline status and subsequent progress of the ABCD III initiative. At follow-up, it will be useful to examine these results in conjunction with other data sources to fully understand progress toward the initiative's objectives.

# Appendix

*Data tables*

*Interview Instrument*



## Data tables

### A1. Number of completed interviews, by site

	Number	Percent
Saint Luke's Pediatric Associates	31	33%
Fridley Children's and Teenagers' Medical Clinic	28	30%
Mayo Pediatrics	24	25%
East Side Family Clinic	8	8%
North Metro Pediatrics	4	4%
<b>Total</b>	<b>95</b>	<b>100%</b>

### Participant characteristics

#### A2. Age of respondents' child

	Mayo Pediatrics (N=24)	Saint Luke's Pediatric Assoc. (N=31)	Fridley and North Metro (N=32)	Total (N=95)
Less than 18 months	4%	26%	19%	17%
19 to 23 months	46%	32%	38%	36%
24 to 35 months	50%	29%	9%	30%
3 to 5 years	-	13%	34%	17%

#### A3. Racial or ethnic background of child

	Mayo Pediatrics (N=24)	Saint Luke's Pediatric Assoc. (N=31)	Fridley and North Metro (N=32)	Total (N=95)
African American	4%	-	13%	9%
Asian	4%	-	-	2%
Hispanic/Latino	4%	-	28%	14%
Non-Hispanic White	50%	97%	47%	60%
Hispanic White	8%	-	3%	3%
Two or more races	30%	3%	9%	12%

Half (50%) of the respondents lived in Greater Minnesota and another 38 percent reside in the 7-county Metro region. The remaining 11 percent lived outside Minnesota, most frequently in Wisconsin cities bordering the state. More specifically, respondents lived in Duluth (18%), Rochester (14%), Blaine (8%), Saint Paul (8%) and Superior, Wisconsin (8%).

---

#### A4. Respondents' distance to clinic

	Mayo Pediatrics (N=24)	Saint Luke's Pediatric Assoc. (N=31)	Fridley and North Metro (N=32)	Total (N=95)
Less than 25 miles	75%	84%	90%	85%
26 to 50 miles	21%	13%	10%	13%
51 miles or more	4%	3%		2%

#### Respondents' relationship with primary care clinic, differences by clinic

- A slightly higher percentage of respondents from Mayo Pediatrics (13%) reported they usually receive care from another provider.
- Patients of Saint Luke's Pediatric Associates were more likely to have a regular doctor or health provider for their child (100%), followed by Mayo Pediatrics (86%) and Fridley Children's and Teenagers' Medical Center and North Metro Pediatrics (81%).
- Respondents<sup>2</sup> were less likely to have seen their regular doctor on their child's last visit at Saint Luke's Pediatric Associates (32%) versus Mayo Pediatrics (17%).

---

#### A5. Length of time child seen at clinic

	Mayo Pediatrics (N=24)	Saint Luke's Pediatric Assoc. (N=31)	Fridley and North Metro (N=32)	Total (N=95)
Less than 6 months	5%	-	-	1%
6 months to 1 year	9%	10%	12%	11%
More than 1 year	86%	90%	88%	88%

## Respondents' use of clinic services in the past year

More than half of families interviewed (55%) had visited the clinic more than four times in the past year. As expected, younger children (under 18 months old) were more likely to have visited more than four times per year (81%).

---

### A6. Total number of visits in the past 12 months

	Mayo Pediatrics (N=24)	Saint Luke's Pediatric Assoc. (N=31)	Fridley and North Metro (N=32)	Total (N=95)
1 time	29%	-	3%	9%
2 or 3 times	46%	29%	37%	36%
4 to 10 times	17%	64%	44%	44%
More than 10 times	8%	7%	16%	11%

---

### A7. Number of well-child visits in the past 12 months

	Mayo Pediatrics (N=24)	Saint Luke's Pediatric Assoc. (N=31)	Fridley and North Metro (N=32)	Total (N=95)
None	17%	-	-	4%
1 time	25%	26%	31%	27%
2 or 3 times	42%	32%	31%	35%
3 or more times	16%	42%	38%	34%

## Information about those referral to multiple services in the past year

Four respondents received dual referrals to Early Intervention/Help Me Grow and a specialist, and in two cases community services as a third referral. The specialists seen in these particular cases were for psychiatry, speech therapy, pediatric development and a hospital referral.

## Additional information about improving service coordination

At the end of the interview, respondents were asked for suggestions about how to improve the way clinics coordinate services with other medical providers, schools, and in the community.



Most respondents (77%) did not have any suggestions for improving coordination, and many used the opportunity to offer comments to express their satisfaction with the care and services they receive:

No [suggestions]. They are doing a great job.

I think they are doing a good job in connecting with patients and following up after.

I think my doctor is fantastic and I wish she could be the doctor for the [whole] family. The clinic is run so smoothly. I can always get an appointment; I only have to wait for about 5 minutes. It's a great place.

The care I've received from the nursing staff [is great]; they know what services we receive and I'm very satisfied with them.

We don't have health insurance. They see my kids for free. That is amazing.

No. I'm really satisfied with the clinic they do a great job.

For me it's perfect.

About a quarter of respondents offered suggestions about the kinds of information about community services and/or enhanced coordination services that would be helpful to them or other comments about services:

Have brochures in the lobby regarding [child] development for 1st time mothers.

If they suggested programs like Early Childhood Family Education (ECFE), I would like to find this out from the Doctor's office.

Offer more information about WIC, Food Stamps and food shelves. Maybe just post information about nutrition and local food banks in the area.

Coordinate with schools so the schools can get whatever they need from the clinic.

Any programs to help pay for medical expenses or payment plans, etc.

1) Advertise on the radio, especially the Spanish radio stations. 2) Have other parents from the schools come to take a tour of the clinic and explain services.

A lot of the patients at that clinic are Spanish speaking, so it would be good to have more Spanish speaking staff.

Have a clinic social worker.

Have a mother's group to talk and learn together at the clinic

Having health fairs in the schools and community.

I just find out if they suggest programs like Early Childhood Family Education. I would like to find this out from doctor's office.

I think it would be better if they've already reviewed the file before you come in; in the past I've had them miss something – and she couldn't be treated in a particular manner because of a past illness.

If they can start sending mail about when shots are due.

It would be nice to have more info made available [no specifics given].

More advertising, send flyers to our homes of events, reminder of services.

Maybe if kids are in daycare...they could talk to the daycare providers.

Should have a monthly class; we should know when shots are due and what "he or she" needs to do.

Tell single mothers what resources are good for them..

The clinic staff should be more patient and really check the child.

To have more information available in the community about their clinics and services.

When my daughter was going through different referrals, someone to coordinate would have been very helpful, because there were a lot of appointments to keep track of and cancelations.

## *Interview instrument*

Project Code: 71255

Client ID#: \_\_\_\_\_

### **ABCD-III (Assuring Better Child Development) Baseline Parent Interview**

NAME OF CLINICS: Fridley Child and Teen Clinic, Fridley, North Metro Peds, Fridley, Mayo Pediatrics, Rochester, Eastside Family Clinic, St. Paul, and Saint Luke's Pediatric Associates, Duluth
---

#### **Introduction: Part A**

May I speak to   [R]  ?

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 4 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

IF PARENT DOES NOT HAVE A CHILD AGED 5 OR UNDER, FAMILY IS INELIGIBLE FOR SURVEY, THANK THEM FOR THEIR TIME, AND TERMINATE INTERVIEW].

2. Is [NAME OF CLINIC] the clinic where [NAME OF CHILD] usually receives care?

Yes.....	1
No..... (GO TO Q. 5a).....	2
Refused..... (GO TO Q. 5a).....	7
Don't know .....	(GO TO Q. 5a)..... 8

3. How long has [NAME OF CHILD] been a patient at this clinic? Would 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 or health provider for [CHILD'S NAME] at [NAME OF CLINIC]?

Yes.....	1
No..... (GO TO Q. 5a).....	2
Don't know .....	(GO TO Q. 5a)..... 8

4b. Thinking about the last time that you took [CHILD'S NAME] to [NAME OF CLINIC], did you see your child's primary health care provider – meaning your child's regular doctor, nurse practitioner, or physician's assistant?

Yes.....	1
No.....	2
Refused.....	7
Don't know .....	8

- 5a. During the past 12 months, how many times was [CHILD'S NAME] seen at [NAME OF CLINIC]? Would you say...
- 1 time, ..... 1
  - 2 or 3 times, ..... 2
  - 4 to 10 times, or ..... 3
  - More than 10 times? ..... 4
  - Refused ..... 7
  - Don't know ..... 8

- 5b. How many of these visits, during the past 12 months, were your child's regular check-up or well-child visit? Would you say...
- None, ..... 1
  - 1, ..... 2
  - 2 or 3, or ..... 3
  - 3 or more check-ups or well-child visits? ..... 4
  - Refused ..... 7
  - Don't know ..... 8

6. In the past 12 months, did your child's doctor or other health providers do any of the following to address [NAME OF CHILD]'s learning or development: This may have occurred at your child's regular check-up or well-child visit.

Did the doctor or other health provider	Yes	No	REF	DK
a. Note a concern about your child's learning or development that should be watched carefully?	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 or development?	1	2	7	8
d. Refer your child for speech-language or hearing testing?	1	2	7	8
e. Have you fill out a questionnaire about specific concerns or observations you may have about your child's physical abilities or ability to communicate?	1	2	7	8

IF NO FOR ALL Q. 6A-6E, GO TO Q. 7  
 IF YES TO ANY Q. 6A-6E, CONTINUE

- 6f. Did you get any advice or plans for next steps?
- Yes ..... 1
  - No ..... (GO TO Q. 6h) ..... 3
  - Refused ..... (GO TO Q. 6h) ..... 7
  - Don't know ..... (GO TO Q. 6h) ..... 8

- 6g. Do you feel comfortable with the advice or plans for next steps?
- Yes ..... 1
  - No ..... 2
  - Refused ..... 7
  - Don't know ..... 8

6h. How satisfied were you with the way your child's doctor or other health providers handled this part of the visit?  
Would you say...

- Very satisfied,..... 1
- Satisfied, ..... 2
- Dissatisfied, or ..... 3
- Very dissatisfied? ..... 4
- Refused..... 7
- Don't know ..... 8

7. In the past 12 months, did your child's doctor or other health providers do any of the following to address [NAME OF CHILD]'s behavioral or mental health: This may have occurred at your child's 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 behavior or mental health that should be watched carefully?	1	2	7	8
Test your child's behavior or mental health?	1	2	7	8
Refer your child for testing of his/her behavior or mental health?	1	2	7	8
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

IF NO FOR ALL Q. 7a-7d, GO TO Q. 8a  
IF YES TO ANY Q. 7a-7d, CONTINUE

7e. Did you get any advice or plans for next steps?

- Yes ..... 1
- No..... (GO TO Q. 7g) ..... s
- Refused..... (GO TO Q. 7g) ..... 7
- Don't know ..... (GO TO Q. 7g) ..... 8

7f. Do you feel comfortable with the advice or plans for next steps?

- Yes ..... 1
- No..... 2
- Refused..... 7
- Don't know ..... 8

7g. How satisfied were you with the way your child's doctor or other health providers handled these parts of the visit?  
Would you say...

- Very satisfied,..... 1
- Satisfied, ..... 2
- Dissatisfied, or ..... 3
- Very dissatisfied? ..... 4
- Refused..... 7
- Don't know ..... 8

- 8a. During the past 12 months, did you have any issues or concerns about your child’s growth, development, learning, behavior, or mental health that you asked about during a visit to the clinic?
- Yes ..... 1
- No..... (GO TO Q. 8c)..... 2
- Refused..... (GO TO Q. 8c)..... 7
- Don’t know ..... (GO TO Q. 8c)..... 8
- 
- 8b. How helpful was the doctor or other health care provider in addressing your concern or answering your questions? Would you say...
- Very helpful, ..... 1
- Somewhat helpful, ..... 2
- They tried to address, but were not helpful, or ..... 3
- They did not address the concern? ..... 4
- Refused..... 7
- Don’t know ..... 8
- 
- 8c. During the past 12 months, did you have any issues or concerns about your child’s growth, development, learning, behavior, or mental health that your doctor or other health providers did not talk with you about, and that you did not ask about during the 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)..... 8
- 
- 8d. What were the concerns?
- \_\_\_\_\_
- \_\_\_\_\_
- 
- 8e. Why did you not discuss these concerns?
- \_\_\_\_\_
- \_\_\_\_\_
- 
- 9a. During the past 12 months, did your doctor or clinic refer your child for any Early Intervention services that the school district can provide? These services are also called “Help Me Grow.”
- Yes ..... 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 from the clinic give you information, like a phone number, so that you could contact Early Intervention or Help Me Grow?
- Yes ..... 1  
 No..... 2  
     Refused..... 7  
     Don't know ..... 8
- 9c. Did your child's doctor or other health providers or someone from the clinic do anything else to help you receive the Early Intervention services from the school?
- Yes (What did they do? \_\_\_\_\_) .. 1  
 No..... 2  
     Refused..... 7  
     Don't know ..... 8
- 9d. Did you bring your child into Early Intervention/Help Me Grow for an assessment?
- Yes ..... 1  
 No..... 2  
     Refused..... 7  
     Don't know ..... 8
- 9e. Did your child receive any Early Intervention or Help Me Grow services? Examples can include occupational therapy, speech services, mental health and other services that the school district provides.
- Yes ..... 1  
 No..... (GO TO Q. 9g) ..... 2  
 Not yet, but will in the near future ..... (GO TO Q. 10) ..... 3  
     Refused..... (GO TO Q. 10) ..... 7  
     Don't know ..... (GO TO Q. 10) ..... 8
- 9f. How helpful have these services been for your child or family? Would you say...
- Very helpful, (GO TO Q. 9h) ..... 1  
 Somewhat helpful, or (GO TO Q. 9h) ..... 2  
 Not helpful? (GO TO Q. 9h) ..... 3  
     Refused (GO TO Q. 9h)..... 7  
     Don't know (GO TO Q. 9h) ..... 8
- 9g. Is there anything keeping your child from getting these services or any reason you would prefer your child not to get these services?
- \_\_\_\_\_
- \_\_\_\_\_



9h. Did your child's doctor or other health providers follow-up with you to find out if your child was getting Early Intervention services?

- Yes ..... 1  
 No..... 2  
 Refused..... 7  
 Don't know ..... 8

10. 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, did your child's doctor or other health providers at the clinic refer you to a specialist or suggest that you see 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 give you information, like a phone number, so that you could contact a specialist?

- Yes ..... 1  
 No..... 2  
 Refused..... 7  
 Don't know ..... 8

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

Yes (What did they do? \_\_\_\_\_) .. 1

No..... 2

    Refused..... 7

    Don't know ..... 8

11e. Did your child go to the specialist?

Yes..... 1

No..... (GO TO Q. 11g)..... 2

Not yet, but will in the near future ..... (GO TO Q. 12)..... 3

    Refused..... (GO TO Q. 12)..... 7

    Don't know ..... (GO TO Q. 12)..... 8

11f. How helpful was the specialist? Would you say...

Very helpful, (GO TO Q. 11h) ..... 1

Somewhat helpful, or (GO TO Q. 11h) ..... 2

Not helpful? (GO TO Q. 11h) ..... 3

    Refused (GO TO Q. 11h)..... 7

    Don't know (GO TO Q. 11h) ..... 8

11g. Is there anything keeping your child from getting these services or any reason you would prefer your child not to get these services?

\_\_\_\_\_

\_\_\_\_\_

11h. Did your child's doctor or other health providers follow-up with you to ask if your child visited the specialist or ask about the visit?

Yes..... 1

No..... 2

    Refused..... 7

    Don't know ..... 8

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
a. The reasons why my child were referred to a specialist was 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

13a. During the past 12 months, did your child's doctor or clinic refer your child for any other services in the community such as a follow-along program, Home visiting, HeadStart, ECFE, Public Health, or other community service?

- 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 ..... 1 No ..... 2 Refused ..... 7 Don't know ..... 8	Yes ..... 1 No ..... 2 Refused ..... 7 Don't know ..... 8	Yes ..... 1 No ..... 2 Refused ..... 7 Don't know ..... 8
IF YES TO 13b-1. THEN: What was that?	_____ _____ _____	_____ _____ _____	_____ _____ _____
Does/did your child receive these services?	Yes ..... 1 Not yet, but will in the future ..... 2 No ..... 3-->Is there anything keeping your child from getting these services (describe)? ____ _____	Yes ..... 1 Not yet, but will in the future ..... 2 No ..... 3->Is there anything keeping your child from getting these services (describe)? ____ _____	Yes ..... 1 Not yet, but will in the future ..... 2 No ..... 3->Is there anything keeping your child from getting these services (describe)? ____ _____

13c. Does your child’s primary care provider or nurse follow-up with you to find out if your child was getting these community services?

- Yes ..... 1
- No..... 2
- Refused..... 7
- Don't know ..... 8

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

	Would you say...					
	Strongly disagree,	Disagree,	Agree, or	Strongly agree?	REF	DK
a. The reasons why my child was referred to community services were explained to me.	1	2	4	5	7	8
b. I have a right to approve all community 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

15a. 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.”

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

15b. How helpful has the Care Coordinator been in coordinating your child’s care among health care providers, Early Intervention/Help Me Grow, or community organizations and staying informed about services your child is receiving? Would you say...

- Very helpful. .... 1
- Somewhat helpful, or ..... 2
- Not helpful? ..... 3
- Refused..... 7
- Don't know ..... 8

- 15c. How satisfied are you with the follow-up the Care Coordinator does with you? Would you say...
- Very satisfied,..... 1
  - Satisfied, ..... 2
  - Dissatisfied, or ..... 3
  - Very dissatisfied? ..... 4
  - Refused..... 7
  - Don't know ..... 8

- 15d. Do you feel that you need someone to coordinate care among your child's different doctors and services?
- Yes ..... 1
  - No..... 2
  - Refused..... 7
  - Don't know ..... 8

16. How often does your child's doctor or primary provider explain things in a way that you can understand? Would you say...
- Never,..... 1
  - Sometimes, ..... 2
  - Usually, or ..... 3
  - Always? ..... 4
  - Refused..... 7
  - Don't know ..... 8

17. Have you received information from this clinic about Food Stamps, WIC, or other community services and financial resources that might be helpful to your family?
- Yes ..... 1
  - No..... 2
  - Refused..... 7
  - Don't know ..... 8

18. The clinic is looking to improve the way it coordinates service with other medical providers, the schools, and in the community. Do you have any suggestions for ways in which your clinic could be more helpful in coordinating with other services?
- 
- 
- 

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

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.

20. How far away from [NAME OF CLINIC] do you live?

- Less than 25 miles ..... 1
- 25 to 50 miles..... 2
- 51 to 100 ..... 3
- More than 100 miles ..... 4
- Refused..... 7
- Don't know ..... 8

21. What is your child's racial/ethnic background? Are you . . .

	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
e. White/Caucasian	1	2	7	8
f. Other (Specify: _____)	1	2	7	8

22. What is the primary language spoken in your home? **(DO NOT READ LIST)**

- English ..... 1
- Spanish ..... 2
- Hmong..... 3
- Vietnamese ..... 4
- Somali ..... 5
- Other (Specify: \_\_\_\_\_) .. 6
- Refused..... 7
- Don't know ..... 8

23. Those are all of the questions I have. Thanks for taking the time to be interviewed today. We really appreciate your help and your time. I have a \$15 Target or Walmart gift certificate to send to you. Would you prefer:

- A Target Gift Card, or..... 1
- A Walmart Gift Card..... 2
- (Don't want a gift card)..... 3

24. We have your address as (FACE SHEET ADDRESS). Is this correct?

- Yes..... (GO TO Q. 26)..... 1
- No..... 2

25. What is your correct address?

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

26. 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 AT HER OWN RISK. THIS MEANS THAT IF THEY DON'T RECEIVE IT, WE WILL NOT REPLACE IT.

Certified..... 1  
Regular mail..... 2

Interviewer: \_\_\_\_\_

Date: \_\_\_\_\_

Interviewer Employee #: \_\_\_\_\_

INTERVIEWER

If interview was completed in language, other than English, please list language: \_\_\_\_\_

If completed in English, please rate the respondent's fluency in English:

Excellent..... 1  
Very good..... 2  
Good ..... 3  
Fair ..... 4  
Poor.....