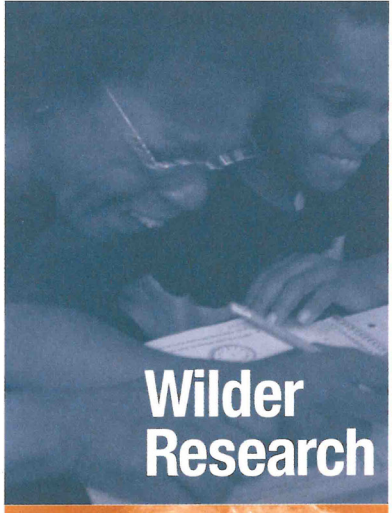

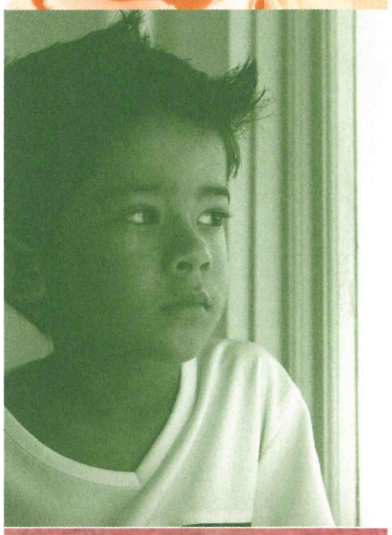

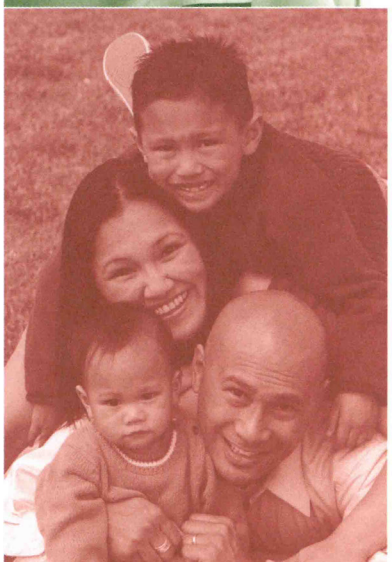

Coordinating Communities for Healthy Development

Lessons learned through Minnesota's Assuring Better Child Development (ABCD III) project

OCTOBER 2012

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Prepared by:
Melanie Ferris and Darcie Thomsen

Wilder Research
451 Lexington Parkway North
Saint Paul, Minnesota 55104
651-280-2700
www.wilderresearch.org

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Mark Anton
Cheryl Bourgeois
Jennifer Bohlke
Walker Bosch
Jackie Campeau
Marilyn Conrad
Michelle Gerrard
Ruth Hamberg
Cheryl Holm-Hansen
Margaree Levy
Lenny Major
Alicia Matos
Nam Nguyen
Amanda Peterson
Margie Peterson
Miquel Salazar
Abby Struck
Dan Swanson
Kerry Walsh
Pa Xiong

Project background

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 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 age birth through 5 years. The project supported four pilot sites (in Anoka, Olmsted, Ramsey, and St. Louis Counties). A variety of strategies were used to enhance care coordination by establishing or strengthening linkages between primary care clinics, school districts, and community-based medical specialists and mental health service providers. If successful, the initiative would result in benefits such as timely access to services for children with potential developmental and/or social-emotional concerns and improved care coordination. The lessons learned through the ABCD III initiative have enhanced Coordinating Communities for Healthy Development (CCHD) project, a broader DHS quality improvement effort intended to increase collaboration and coordination between primary care and early intervention services throughout the state.

Structure of the report

This report is the final report for the project and is intended to: 1) describe the implementation efforts of the four pilot sites, including their accomplishments and challenges; 2) report the impact of these efforts, including changes in the number of youth screened and referred to early intervention services, and the timeliness of communication back to the clinic; 3) identify steps the pilot sites are taking to sustain and spread their efforts; and 4) provide recommendations to local partners for enhancing their efforts and to the Department of Human Services (DHS) and other state agencies for supporting improved linkages between primary care and early intervention services across the state.

Evaluation methods

A multi-method evaluation approach was used to not only track and report changes in referral patterns, care coordination efforts, and communication between medical providers and school districts, but to also understand the experiences of parents and factors that influence implementation of a new model of care coordination. The methods used throughout the full evaluation are briefly described below:

- **Key informant interviews:** Each year, a series of key informant interviews was conducted with key stakeholders from each project, including the clinic's provider champion and care coordinator, early intervention/school district staff, and other key project partners. The interviews were used to identify recent project accomplishments, challenges, and plans for spread and sustainability. The key informant interview protocols for the final round of stakeholder interviews are included in the report appendix.

- **Clinic screening, referral, and communication data:** All clinics were asked to use an Access database developed by DHS, to monitor and report screening, referral, care coordination, and communication information for children in the project's target population. The databases were submitted to Wilder Research every six months and reported annually. The database was used as a care coordination tool for some clinics, while others used it only to meet evaluation reporting requirements.

- **Parent interviews:** Telephone interviews were conducted with a random sample of parents from each participating clinic whose child (age 0-5) was screened during the last 12 months. Interviews, designed to gather information from the patient perspective about the screening process itself and the referrals made by the child's provider, were conducted during the first year of the initiative and again in the final (third) year of the project. The final round of interviews also included a targeted sample of parents whose child was referred for early intervention services during the past year. This report highlights only a few key findings from the parent interviews. A comprehensive technical report provides more information about the limitations of this evaluation component and additional key findings.

In addition, a few short term evaluation activities were used over the course of the project to explore a specific issue or gather feedback from a different group of stakeholders at a key point in the project.

- **Interviews with Minnesota Department of Education (MDE) staff:** Key informant interviews were conducted with four MDE staff members who have been involved with restructuring the early intervention system and developing the state's Help Me Grow referral system. This data collection activity was added specifically for this Year 2 report, as some information about the restructuring was needed to provide greater context to the implementation efforts described by some of the pilot sites.

- **Referral tracking by early intervention staff:** An Excel spreadsheet was developed to assist early intervention staff in monitoring the referrals that came to their office from the participating clinic, their assessment of the appropriateness of the referrals made, and a description of the final assessment outcomes and future service plans.

This tool was discontinued in 2011, when the role and responsibilities of early intervention staff shifted as a result of the statewide restructuring.

ABCD III within a broader context

The evaluation for this initiative focuses on the work done by each pilot site to develop and implement a sustainable model that improved care coordination and communication between school districts and primary care clinics. However, there were also a number of factors that influenced the work of the pilot site teams, both directly and indirectly. With few exceptions, the potential influence of these factors on the work of the teams was not addressed through the evaluation. However, this additional information provides a background to understanding the broader environment in which the pilot sites were working to change the way services are delivered.

- The pilot sites were selected through an RFP process and therefore received a small, but important, financial stipend for participating.
- The pilot sites received technical assistance and support from DHS throughout the course of the initiative, including the invitation to participate in three "learning collaborative" meetings.
- The initiative was implemented as a quality improvement effort by clinics. In addition, DHS staff worked with medical providers to gather data used to meet their individual Maintenance of Certification (MOC) requirements from the Medical Board of American Pediatrics.
- Halfway through the initiative, the Minnesota Department of Education (MDE) rolled out a restructuring of the state's early intervention system. As described in the report, this change did lead to significant changes in staffing roles and responsibilities for two of the four pilot sites.
- Due to changes in staffing at DHS, multiple project coordinators worked directly with the pilot site teams during the course of the initiative.
- Care coordination activities have been encouraged and promoted through the state's Health Care Home certification program and national health care reform efforts.

Looking back: Lessons learned through the ABCD III initiative

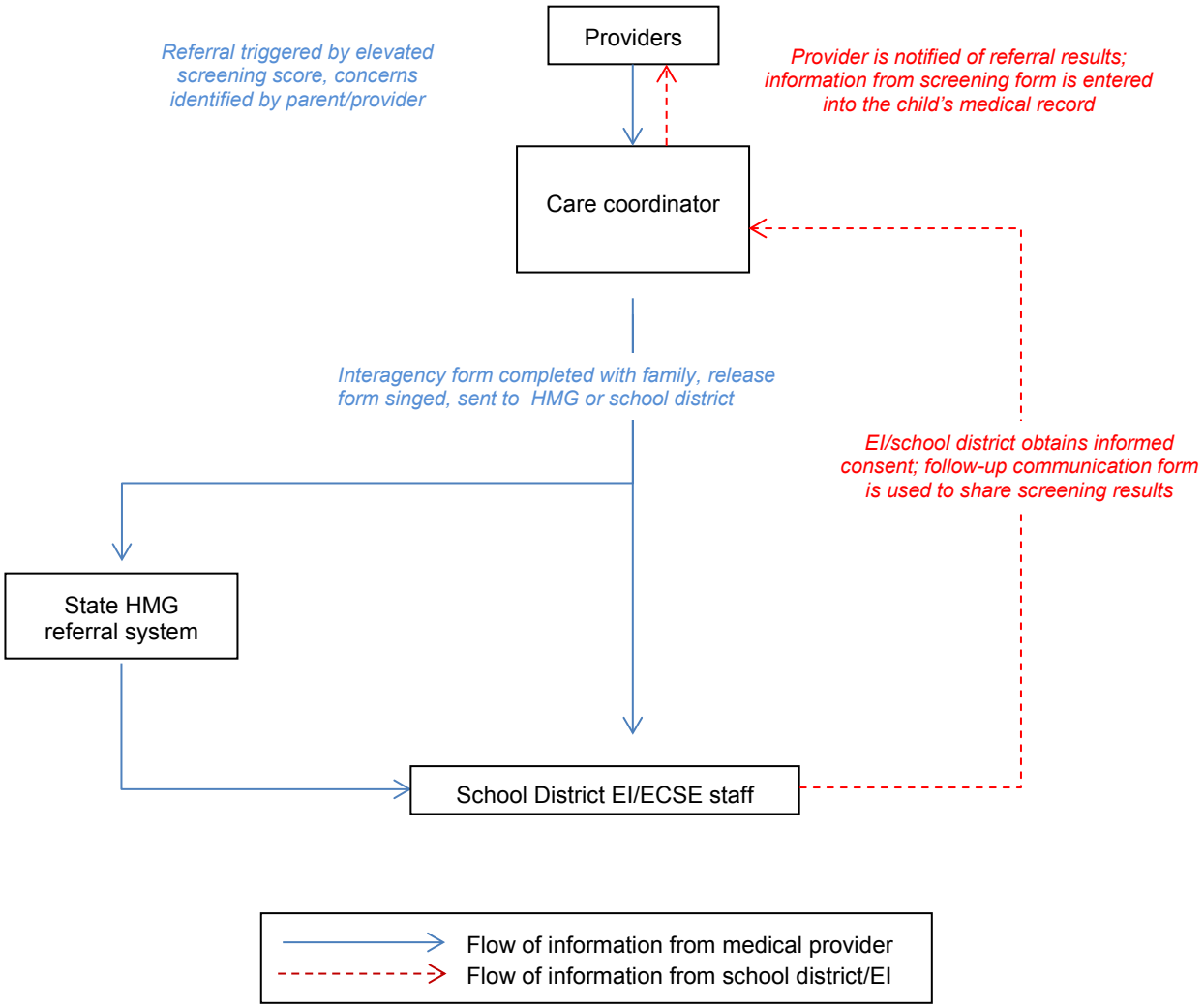
The four pilot sites that participated in the ABCD III initiative shared common goals, but all began their work at different stages of readiness and with varied levels of existing relationships between primary care and local early intervention services. In this section of the report, we focus first on describing the activities and unique attributes of the four pilot sites and then highlight key lessons learned through the initiative related to referral, care coordination, and communication practices.

Site-specific summaries

Four sites were selected to participate in the ABCD III initiative. Each site team included representatives from at least one clinic and one school district, along with other community stakeholders including local public health departments and Head Start. The teams represented the following four counties: Anoka, Olmsted, Ramsey, and St. Louis.

In many ways, the four sites shared common processes and encountered similar barriers in implementing their models. At a minimum, all four project teams included a provider champion, clinic care coordinator, and one or more representatives from the partnering school district(s), though their roles and responsibilities varied by site. All sites used consistent screening protocols to identify children who may be eligible for early intervention services and developed communication forms and processes to help ensure the clinic would receive information back from early intervention services (Figure 1). Although all sites were interested in developing a shared two-way release of information process, none of the sites were able to develop a form or process that eliminated the need for parental consent to be obtained by both the clinic and the school district. However, the sites did each develop a shared communication form to share clinic screening information and school assessment results once consent had been obtained. Common implementation challenges across the pilot sites included barriers communicating across systems, consistency in using the follow-up communication form to share results with the clinic, and staff turnover.

1. General referral and communication process between clinics and early intervention services



Understanding the common characteristics and unique aspects of each pilot site's referral and communication model provides useful context to interpret the screening, referral, and communication data submitted by each team; identify ways to overcome common challenges; and consider factors that contribute to or hinder future plans for sustainability and spread. While the report identifies specific challenges and strengths with the approach used by each pilot site, we do not recommend one implementation strategy over another, as each model was developed to build on the strengths of local partners and their communication and staffing preferences.

Ramsey County

Brief description

The Ramsey County pilot site underwent some major changes in the first two years of the project, but has successfully developed a coordinated referral and communication process that they are working to spread into new school districts and clinics. Early in the project, implementation was delayed when the initial clinic partner ended its involvement with the project and was replaced by a new clinic. One year later, the responsibilities of early intervention staff working in the county's Help Me Grow central intake office changed significantly as a result of the state restructuring. Despite these challenges, the team developed a referral and communication model that that they plan to sustain after the ABCD III initiative ends. Overall, most members of the team felt they had been very successful in their work, although some were disappointed that their screening, referral, and communication processes hadn't spread into as many school districts in the county as initially hoped for.

Clinic referral and communication practices

The participating clinic, White Bear Lake HealthPartners Clinic, administers the Ireton Child Development Inventory to screen children for potential developmental concerns and uses the Ages and Stages Questionnaire – Social Emotional version (ASQ:SE) less frequently to identify potential social-emotional development concerns. The provider may talk to the parent about early intervention services after developmental concerns are raised or following an elevated screening score. A referral form is completed by care coordinator and parent and faxed directly to the county's central office or to the appropriate school district via the state's online Help Me Grow system. During the final year of the initiative, a medical office assistant began to assist the clinic care coordinator in submitting the referral forms. Referrals to specialty medical providers follow a different process and do not usually involve the clinic care coordinator. However, the clinic does use an active referral process; the medical office assistant typically works with parents to contact these agencies and schedule appointments, if they are interested in this type of support.

Early intervention intake and communication processes

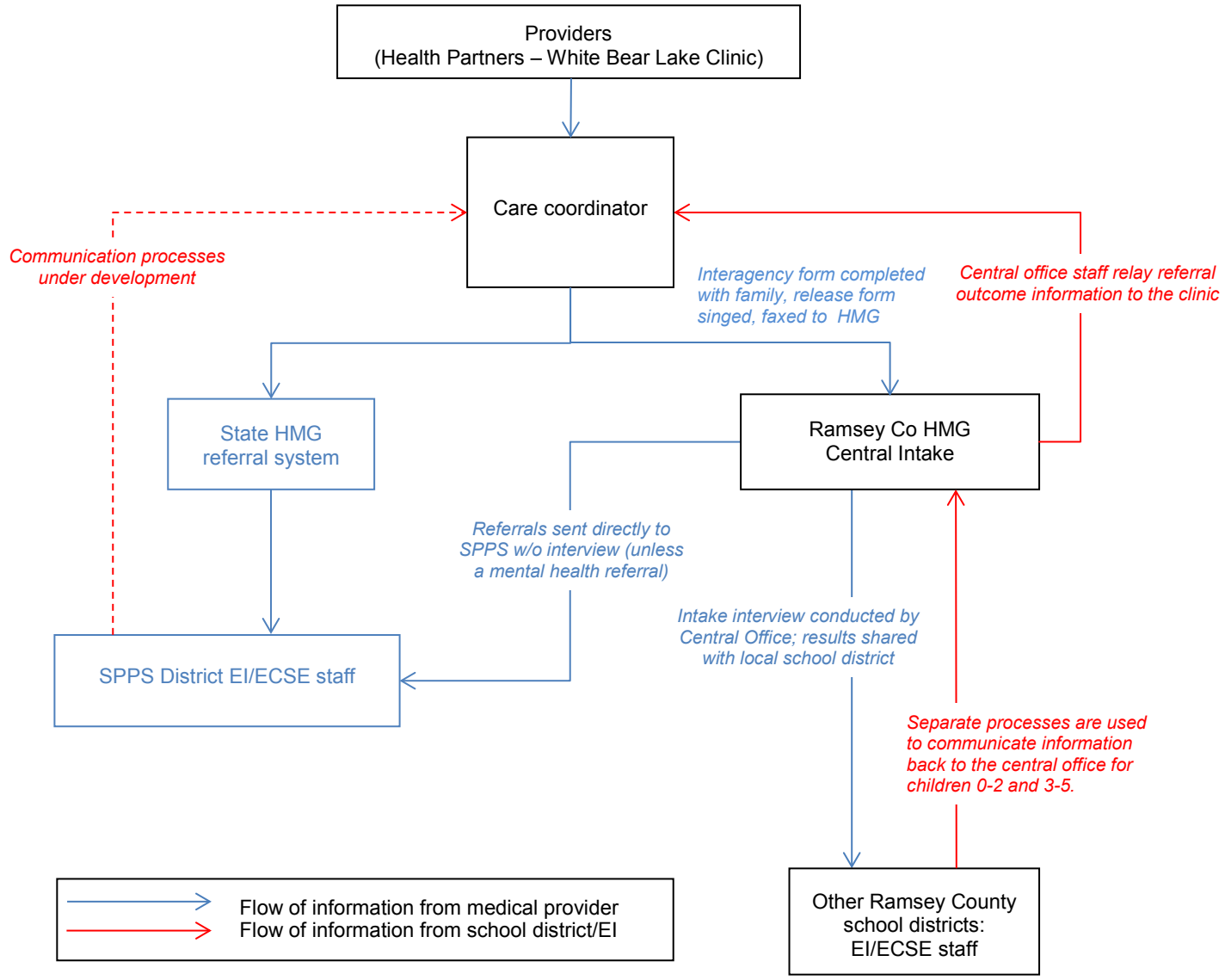
When referrals come to the Help Me Grow central intake office, two different processes can occur, depending on the district the child is enrolled in (Figure 2). For most districts in the county, the central intake office conducts an initial intake assessment and then passes that information along to the appropriate school district's early intervention staff. The central office staff also review the release of information form with the parent to

make sure they feel comfortable with information being shared with their provider before a communication form is returned to the clinic. For Saint Paul Public School (SPPS), the county's central intake office does not have a role in the intake process and simply passes the referral along to the appropriate school staff person for follow-up.

This variability in how referrals are handled by the central office resulted from the state's restructuring of the early intervention system in 2011. Prior to the restructuring, central intake office staff played a key role in conducting the initial intake assessment, sharing that information along to the appropriate school district, monitoring the status of the referral, and communicating results from the assessment and recommended referrals/ treatment to the referring clinic. Following the restructuring, some districts took on the responsibility for conducting the full assessment and following up with the clinic. Now, referrals that come in to the central intake office for those districts are simply passed along to school district staff for all intake, assessment, and follow-up. This change has led to more diffused responsibility for communicating information back to the referring clinic, particularly within the county's largest school district, SPPS. During the past year, representatives from SPPS have started to attend team meetings and become engaged in the project. The team hopes that, through their increased involvement, barriers to the communication feedback loop for that district can be identified and addressed.

The lingering impacts of past initiatives also created a foundation that encouraged communication between schools and clinics for some children. In the past, the central office also had provided direct service coordination to children ages 0-2. While that function ended before the ABCD III initiative began, some school district staff had continued to provide follow-up information to the central office for children ages 0-2. As a result, the communication loop was already in place for some school districts and simply needed to be formalized. However, because that practice wasn't in place for older children (ages 3-5) and different school district staff may work with these students, it has taken more time and effort to formalize a feedback loop for children ages 3-5.

2. Ramsey County: Referral and communication flowchart



Accomplishments, challenges

Overall, the team considered their work to be successful across multiple measures. All team members felt the team had been successful in better ensuring that young children receive appropriate early intervention services, and developing a plan to sustain their work after the initiative ends. The team had more mixed reactions to their overall success in developing a model to improve relationships and communication between clinics and schools. While all felt this work had been very successful with some school districts in the county, some team members had higher expectations around spread and noted disappointment that the model had not been adopted by all school districts in the county.

All providers within the clinic use the same process to screen children and make referrals to early intervention services. In addition, the team's provider champion has shared some of the work done in their clinic with other practitioners within their health care system. The provider champion felt that greater follow-up by school district staff to the clinic would help reinforce these changes for providers not involved in this pilot project, as would immediate confirmation of referrals made through the online system.

The clinic's electronic medical record (EMR) system was enhanced to provide parents with more information about the services their child can receive. When a provider refers a patient to early intervention services, changes to the drop-down menus available in the EMR now allow the provider to insert information about early intervention services, as well as contact information for the child's school district and the state's Help Me Grow website, into the visit summary that is given to parents. In addition, the visit summaries for all 3 year old patients now include information about early childhood screening.

Face-to-face meetings were critical to building relationships across agencies. Team members acknowledged their monthly team meetings were time consuming, but felt the relationships that formed out of these meetings helped to improve relationships between individuals and across agencies. Personal communication, rather than a more general email invitation, was needed to encourage representatives to attend meetings and learn more about the project. Although the team plans to continue meeting in the future, some were concerned that participation might be harder to maintain after the ABCD III initiative ends and that it could be challenging for new school districts or clinics to invest time in meetings.

Changes in practice were hard to observe, given the small size of the clinic's patient population. All pilot teams were encouraged to incorporate quality improvement efforts into their work. However, because only a few children were referred to early intervention services each month, some team members felt it was difficult to observe and monitor changes in practice. The low and inconsistent volume of patients also made it difficult for the care coordinator to maintain dedicated time to follow up on referrals and other coordination activities.

Community-level service gaps were also identified as barriers to service delivery and coordination. Team members noted it was difficult to meet the needs of bi-lingual/ bi-cultural families and to find appropriate preschool settings for all children, due to a lack of available services in the community. Clinic staff also noted that transportation services are difficult to find, but are needed by many lower-income families to attend appointments.

Olmsted County

Brief description

Olmsted County successfully developed a coordinated referral and communication model that they plan to sustain after the initiative ends. Although communication back from some school districts can be less consistent than they ideally desire, they are working towards improving consistency of follow up. They are now working to spread the process to additional medical provider systems and other community partners, such as Head Start and local public health programs. A unique aspect of the work of this site has been their efforts to improve coordination of screening activities in the community. As a result of improved relationships and processes for sharing information, community organizations that do screen children for developmental/social emotional concerns obtain parental consent to send those results to the child's clinic, where it is added to the child's medical record. Overall, most members of the team felt they had been successful in their work, although some felt that the initiative would have a more powerful impact on the local early intervention system if more community partners were involved.

Clinic referral practices

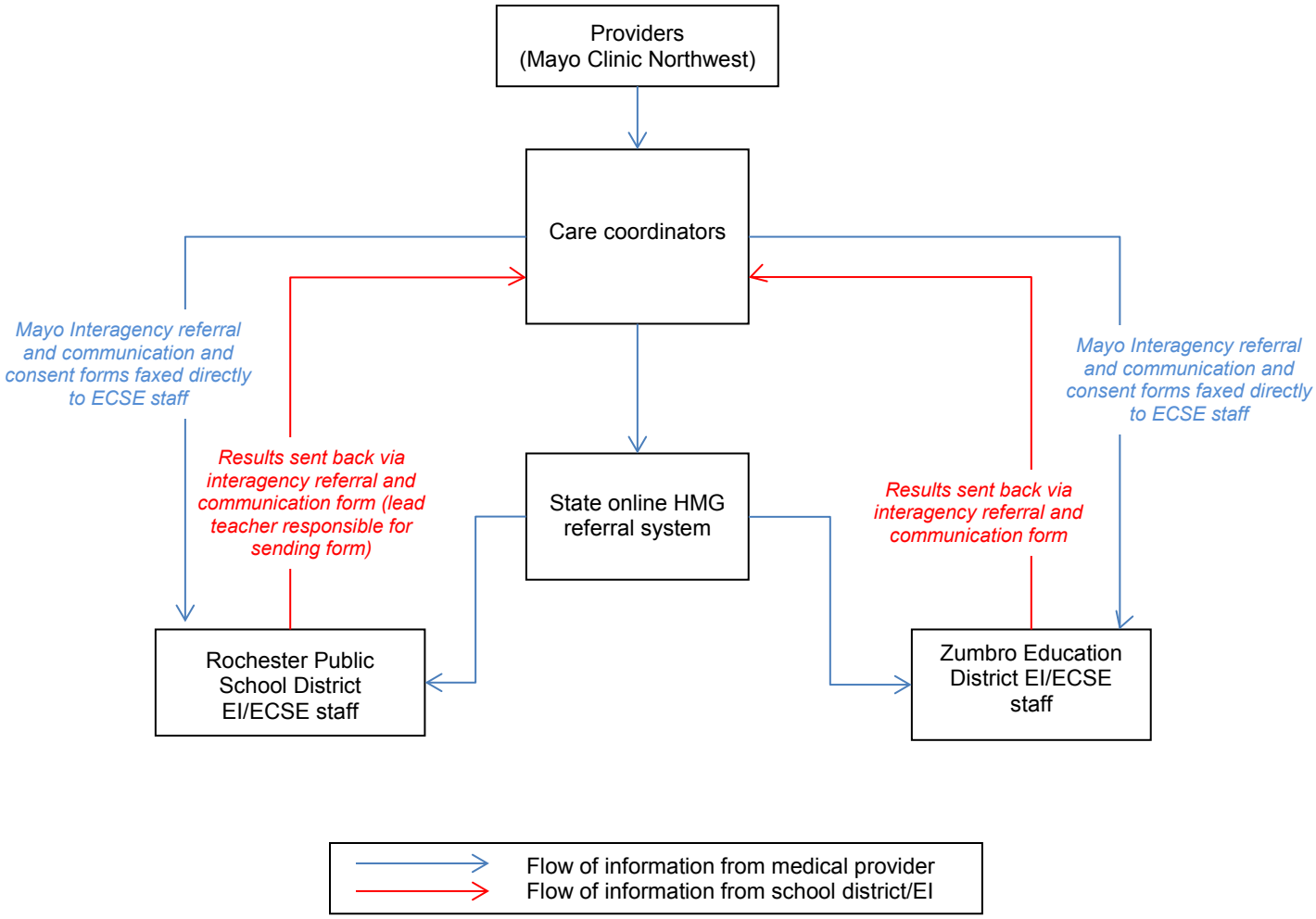
Staff from the Mayo Clinic, the team's clinic partner, administers the Ireton to screen children for potential developmental concerns. The Ages and Stages Questionnaire: Social-Emotional (ASQ:SE) and the Modified Checklist for Autism in Toddlers (M-CHAT) are mailed to parents near the child's 18-month birthday to further identify children who may benefit from more thorough social-emotional, developmental, or autism evaluations. The developmental screening coordinator tracks and integrates all assessment results into the child's EMR. When a child has an elevated screening score or the parent has concerns about the child's development, the clinician places an order for referral through the EMR system. Next, the developmental screening coordinator completes an informed consent form and the Interagency Referral & Communication Form with the family, enters the referral into the state online Help Me Grow referral system, and faxes the completed forms directly to the local early intervention offices (Figure 3). Concerned about potential duplication of services, referring providers typically avoid dual referrals to both early intervention services and medical specialists.

The clinic care coordinator plays a unique role at this pilot site. In addition to coordinating referrals and the flow of information to and from the clinic, the pilot site's care coordinator also serves as a developmental screening coordinator. This role allows someone at the clinic to integrate the clinic's screening process with other early intervention efforts underway at the pilot site.

Early intervention intake and communication processes

Early intervention staff from each school district are responsible for communicating information back to the clinic. After referrals are received, the intake staff at each local school district is responsible for contacting the developmental screening coordinator to confirm that the referral was received. Next, the early intervention staff contact the family for an intake interview. After the intake interview is completed, evaluations are conducted for those children whose intake interviews indicate a need for further assessment. For those children whose intake interviews do not indicate a need for further evaluation, a summary of results is sent to the referring clinician. Similarly, when an evaluation is completed, a summary is sent to the referring provider. Intake and assessment staff may also refer the family to community resources to address other specific needs throughout the intake and evaluation process.

3. Olmsted County: Referral and feedback communication flowchart



Accomplishments, challenges

Through the initiative, referral and communication processes between the early intervention and clinic staff have been established and implemented. The pilot site team has developed a communication form team members use to communicate information about the child throughout the referral and assessment process. The referring clinic sends the form to the local early intervention site when making referrals, to provide specific information about the nature of the referral, and to indicate what information the referring clinician would like to receive about the outcome of the referral. The developmental screening coordinator enters information from the communication form into the EMR and the system notifies clinicians when the updates have been made to the patient's record.

Throughout the initiative, the use of the state online Help Me Grow referral system increased. Beginning in the second year of the initiative, the referring clinic began using the state online referral system for all referrals to early intervention services. When making referrals to the state online referral system, the clinic simultaneously faxes a consent form that allows the provider to release additional information to local early intervention staff and alerts them that a referral has been made. Overall, the information received from the clinic was considered adequate; however, representatives from the clinic felt that communication after a referral is received could be improved. Although the online Help Me Grow system sends an automatic email to the clinic, alerting them that a referral has been received, it doesn't confirm which school district received the referral or provide contact information for the appropriate district staff, limited the clinic's ability to proactively follow up on referrals. From the clinic perspective, it is unclear whether they don't hear back on a referral because the district didn't complete the forms or because the clinic never received the referral.

Through the initiative, the pilot team has increased collaboration with community providers in order to reduce the number of families who complete duplicate screenings. Prior to participating in the initiative, there was little communication between the school district's screening program and the clinic. As a result, many families were being asked to complete the same screening tool multiple times (from the clinic and as part of the district's early childhood screening). To minimize paperwork burden for families, the district now sends all early childhood screening results for children who are patients of the clinic and that information is entered in the EMR. Additionally, clinicians now receive prompts through the clinic's EMR system to refer children who are approaching their third birthday to their local school district for early childhood screening.

The pilot site is making plans to sustain changes in practice after the initiative ends. Pilot site representatives have worked to identify the elements of the initiative that will be most critical to sustain after the ABCD III initiative ends. For example, partners will continue to use the Interagency Referral and Communication Form. Although they acknowledge that in-person meetings will be difficult to schedule, pilot site representatives felt that sustaining the in-person meetings would be essential to maintaining progress, especially as partner sites begin to experience staff turnover. The pilot site is working to incorporate quarterly meetings, which may coincide with other convening in the community, into their sustainability plan.

The pilot site has taken steps to spread the initiative to additional community partners. The team has taken steps to reach out to another major medical provider in the community to share information about the initiative and steps that they can adopt in their work with patients. The provider group has shown interest in learning more about the changes in practice that the pilot site partners have adopted. Pilot site representatives

have also begun working with other community agencies that serve young children and their families, and hope to replicate the referral and communication processes currently used by pilot site partners. Site representatives acknowledge that additional partners can create a more complex process, but feel as though the initiative will have a much stronger impact on families and children when more community partners are involved.

Complex data privacy regulations make it difficult for school districts to send updates on all referrals. Both clinic and school district representatives noted limitations with being able to follow up on some referrals. For example, when families refuse school district services, or when school districts are not able to find families, they are also typically not able to get a signed consent form from the family allowing them to send information back to the clinic. Representatives noted that clinicians, who always receive information back about referrals made to medical specialists, may not understand school district data privacy regulations. Therefore, some clinicians may feel as though school districts have not taken their referral seriously, or have not complied with the assessment and evaluation timeline.

Other lessons learned

Collaboration with community members led to shared learning and increased momentum for all partners. Pilot site representatives felt as though the collective learning that took place throughout the initiative was essential to creating shared goals and garnering buy-in from all partners. For example, representatives felt as though clinicians were more comfortable making referrals to early intervention services after they learned about the services available through the school districts, and about the assessment and evaluation process that is used to determine eligibility for services. Furthermore, the addition of other community partners, including Public Health and other early childhood service providers, created community momentum around the broader goal of better serving young children and their families.

St. Louis County

Brief description

The St. Louis County team has successfully implemented a coordinated communication and referral system, and is working to spread to new community partners and clinics. Pilot site representatives noted ongoing challenges with consistently closing the feedback loop from school districts to clinics, but feel as though they have made progress in the last year. The team plans to sustain their communication and referral model after the ABCD III initiative ends. Overall, pilot site team members felt they had been very successful in their work, but noted that more work was needed to create a formal plan to

sustain and grow their work after the ABCD III initiative ends. During the final year of the initiative, early intervention staff worked to share information about their work with another large medical provider, while the clinic has begun to use communication forms and active referral practices when referring to other agencies, such as public health programs and Head Start. Work has also been done to reach out to other school districts.

Clinic referral and communication practices

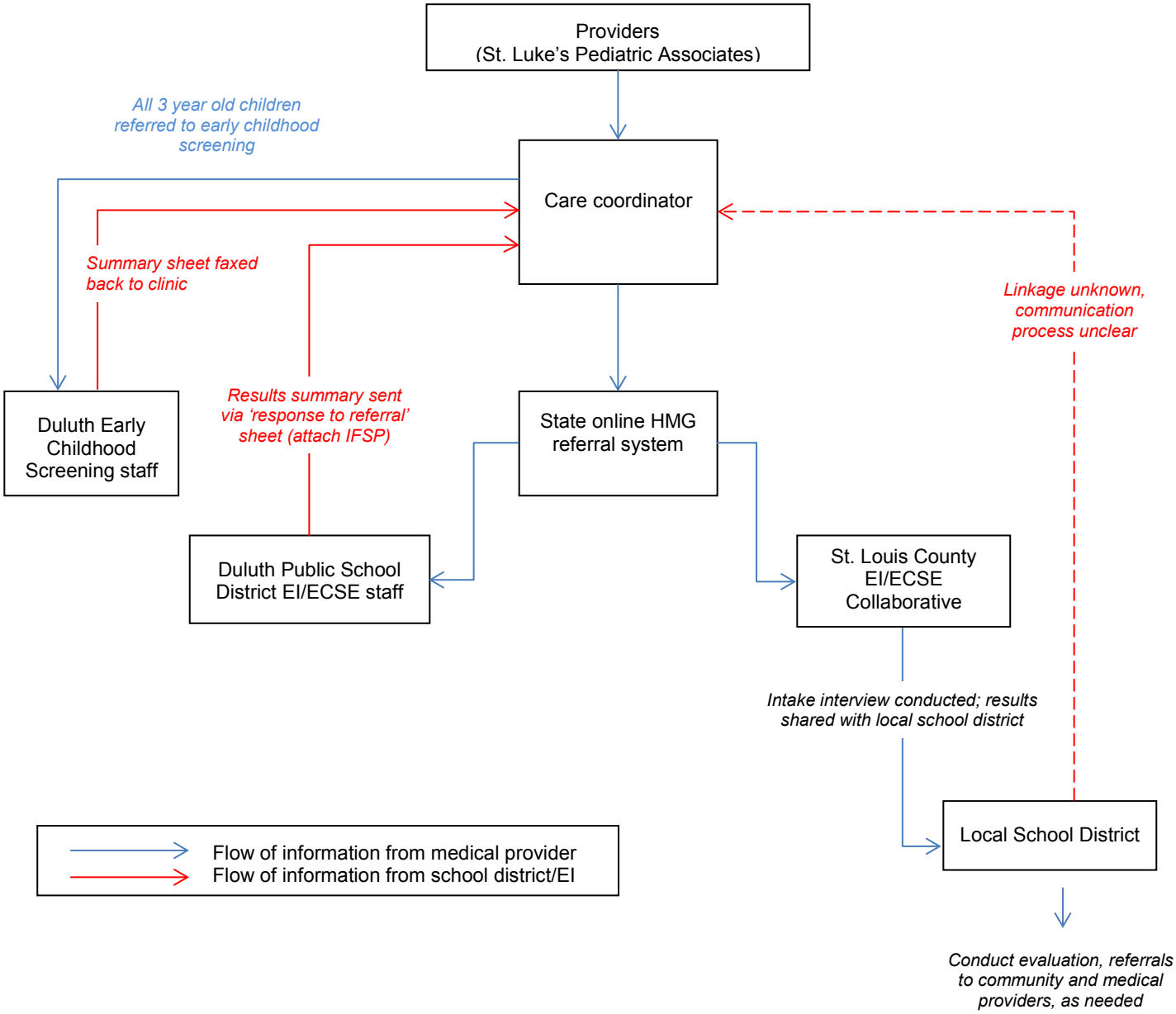
Providers at St. Luke's Pediatric Clinic, the pilot site's participating clinic, administers the Ages and Stages Questionnaire (ASQ) to screen children for potential developmental concerns during all well-child visits. When a child has an elevated screening score or has concerns that suggest a need for early intervention services, the clinician places an order for referral through the EMR system. The clinic care coordinator completes an informed consent form with the family, and enters the referral into the state online Help Me Grow referral system. When information is returned from the school district, the care coordinator receives the form and sends the information to the physician for review and sign-off before it is scanned into the child's EMR.

A unique aspect of this site's screening process is the coordination between the clinic and largest school district's early childhood screening program. Providers at the clinic receive an alert through the EMR when a child is 3 years old and due for an early childhood screening assessment. The clinic makes active referrals to the school district and now, as a result of a communication form developed during the ABCD III initiative, receives screening results back from the district.

Early intervention intake and communication processes

There are two centralized referral intake points within the county, one for the largest school district (referred to as the city central office in this summary) and one centralized contact point for a coordinated group of smaller school districts (the county central office) (Figure 4). When early intervention staff from either central office receive a referral from the clinic, they often call the care coordinator to confirm that the referral was received. The early intervention staff then contacts the family for an intake interview. For the city central office, intake staff also conduct evaluations for those children whose screening interviews indicate a need for further assessment and communicate this information back to the clinic. When referrals are received by the county central office, an initial interview is conducted and the intake staff provide a summary to the appropriate school district to provide them with additional background information before they contact the family to schedule an evaluation. Local school district teachers who conduct evaluations are then responsible for sending a summary of evaluation results back to the referring clinic.

4. St. Louis County: Referral and feedback communication flowchart



Accomplishments, challenges

Through the initiative, local school districts have begun communicating assessment results back to referral sources. Prior to participating in the initiative, there was little communication between local early intervention staff and the clinic. As a result, clinicians were concerned that their referrals to early intervention services were not perceived as critical. As a result of the initiative, the pilot site has developed communication forms

that succinctly summarize the results of each referral. School districts send these forms back to the clinic, and the care coordinator documents screening and assessment results in the child's medical record.

Pilot site partners have a better understanding of the screening, assessment, and evaluation processes used at partner sites. For example, early intervention representatives reported that they move more quickly into an evaluation when receiving referrals from the partner clinic. Pilot site representatives reported knowing which screening tools partner sites use, and feeling confident that the screening results they receive from partner sites are accurate. As one representative said, "Whenever we get a referral from St. Luke's…we'll go straight to evaluation. They know that if St. Luke's referred, the child will likely be eligible."

More work is needed to ensure physicians receive feedback from all referrals. Local early intervention coordinators have begun encouraging the clinic to fill out school district approved consent forms, in addition to clinic consent forms, when making referrals. This allows the school district to provide information back to the clinic about all referrals, including when the family refuses services or when the school district is unable to reach a family.

The feedback loop is being closed more consistently. Early in the initiative, the pilot site created a response to referral form for communicating information. Pilot site team members noted that they have increased the use of the response to referral form in the last year. Clinic representatives noted increased consistency in receiving information back from early intervention staff.

Anoka County

The Anoka County team has experienced a number of staffing changes during the ABCD III initiative that interrupted referral and communication processes. Similar to Ramsey County, a coordinated central office played a significant role in facilitating all early intervention referrals and ensuring follow-up communication was shared back to the referring clinic. The restructuring led to major changes within the central office and moved the responsibility for follow-up communication from a centralized point of contact to the school district teachers who ultimately conducted the assessments and worked with the family to develop a treatment plan. The pilot team included two clinics and a single school district in the county, with the intention to spread into more school districts over time. However, one of the clinics never served any children enrolled in the partner school district, and spread into other districts has been slow. Despite these challenges, the site has developed referral and communication forms and processes that they plan to continue using. However, the team members have very mixed feelings about

the overall success of the initiative. Each partner plans to continue using the forms and processes established through the initiative. However, most members of the team felt they were unlikely to continue meeting together regularly.

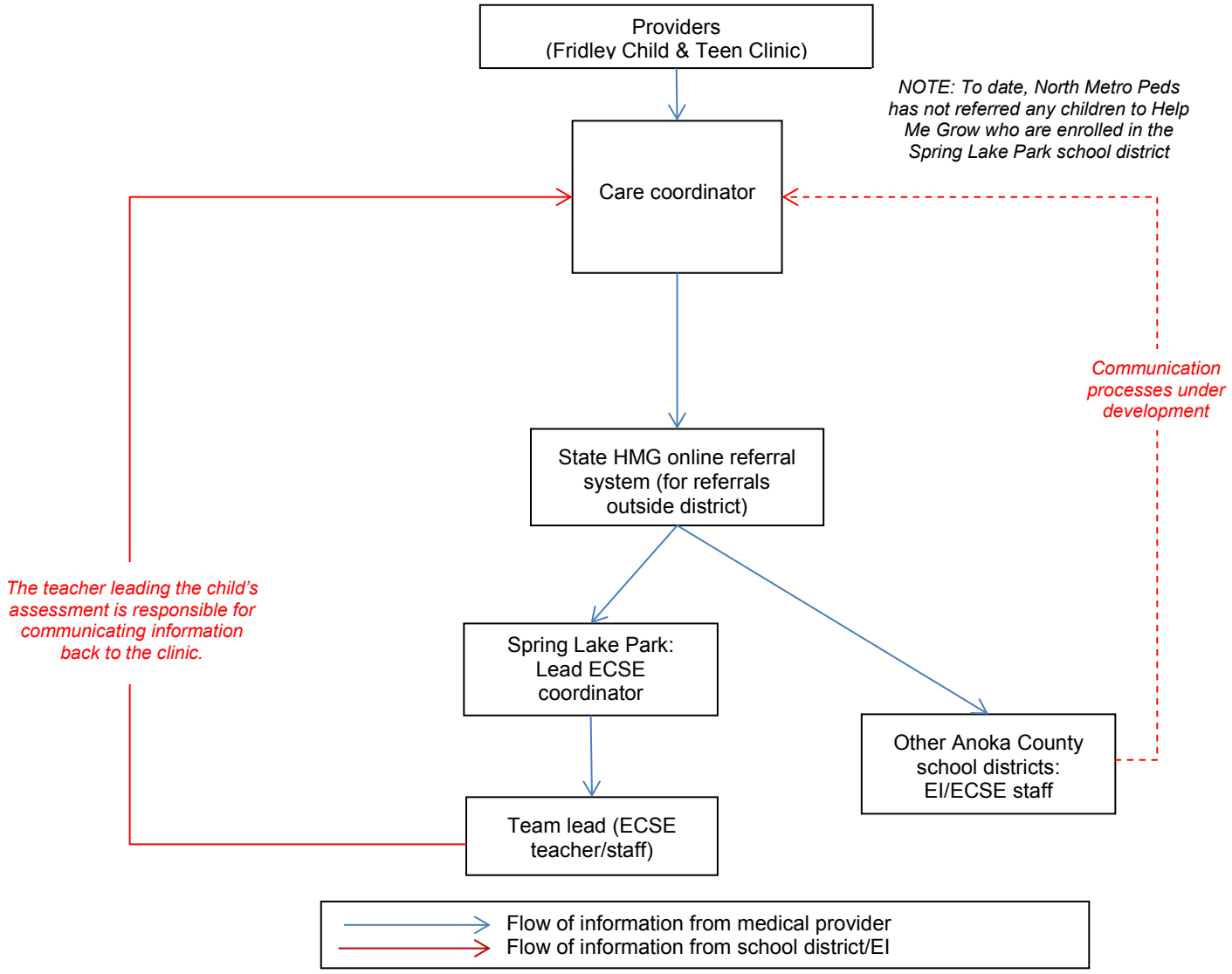
Clinic communication and referral processes

Both clinics that participated in the initiative have screening and referral protocols in place that are being used by all clinic providers. When an elevated screening result or concerns raised by the parent suggest the need for early intervention services, the provider discusses that option with the parent and refers the child for services. Both clinics now use the state online Help Me Grow system to make referrals, a change from faxing the form to the county's central office (Figure 5). Although the care coordinators at both clinics had a role in receiving information back from early intervention services, alerting the provider, and ensuring the information was documented in the EMR, one clinic noted that sometimes communication may be routed directly to the provider, making it more difficult to monitor the outcomes for all children referred.

Early intervention intake and communication processes

Prior to the restructuring, the county's central office conducted an initial intake interview to gather additional information from the parent which was then shared with the district. Although the county's central office is still involved in the project, they provide a supporting role, encouraging school district staff to regularly communicate back to the clinic and participating in team meetings, but not having direct responsibility for communicating information between the clinic and schools. Referrals from the state Help Me Grow system are received by the district's lead early childhood special education coordinator and assigned to a teacher or school staff member who coordinates the assessment and works with the family to develop a service plan, as appropriate. Each individual teacher or staff member is responsible for using the communication form to share information back to the referring clinic. Although the pilot study has focused primarily on improving the relationship between their school district and two local clinics, teachers and staff have been encouraged to always send a communication form back to the referring provider, regardless of which clinic they are affiliated with.

5. Anoka County: Referral and feedback communication flowchart



Accomplishments, challenges

Forms have been developed and modified to meet the evolving needs of the team. The team has developed a referral and follow-up communication form that is being used by school district staff to share assessment outcomes and referral information with the clinic. Initially, the form was used to communicate twice with the clinic, once after the intake interview was completed by the central office and again after the assessment was completed by school district staff. It was modified to reflect their change in process and to ensure consistency in process for children 0-2 and 3-5. Other modifications to the form are being considered as new school districts have started to become involved with the initiative.

Steps have been taken to expand the initiative into new school districts. Initial meetings have been held with other school districts in the county to share information about the initiative and the forms used to provider information back to the clinic. It is not clear how those relationships will be supported as the initiative ends.

Focusing the initiative on only one school district presented both opportunities and challenges. From one clinic's perspective, focusing their process on only children enrolled in one small school district was helpful, as it kept care coordination needs manageable. However, for both clinics, because of the small number of children enrolled in that district, it meant that providers who were following the same screening and referral process rarely received communication back.

Mental health services, as well as services for children from low-income families, are gaps in the county's system. At one clinic, the care coordinator noted that referrals for mental health services are typically made to the county's crisis response center because wait times for other mental health services were too long. The other clinic noted that, because many of their patients are from low-income families, there is always a need for free or low-cost services and supports for families.

Key findings: Screening and referral practices

> Before [ABCD III] I would not have referred a premature birth to Hel p Me Grow. I used to think that I could identify a child with a delay, but now I refer more at-risk children. —*Clinic provider champion*
>
> My light bulb moment was when I realized that [providers] are used to getting information back after a referral. We – the schools – need to do it because it works, the providers expect it, and it helps families. —*Early childhood provider*

As described in the site summaries, all participating clinics had adopted consistent screening and referral protocols among providers in their practice by the end of the initiative. However, there were some differences in the screening process used by each site, particularly in the degree to which they coordinated with other community agencies to ensure all children were screened for delays by age 3.

Approximately four in every five youth referred to early intervention services had an elevated screening score. Referrals to early intervention services can be the result of an elevated screening score, concerns raised by the parent or provider during an appointment, or because the child had a condition which automatically qualifies them for services. Overall, of the 180 children (ages 0-5) referred by their provider to early intervention services, 81 percent had an elevated screening score (Figure 6). Fewer youth (N=93)

were referred to a specialty medical provider or community agency overall, and most of these referrals (58%) did not follow an elevated screening result.

The use of dual referrals made to both early intervention and medical/community-based services varied widely across clinics. Although DHS staff hoped to encourage the practice of dual referrals through the ABCD III initiative, the practice was not widely adopted by the participating sites. Overall, only 20 percent of children were referred to both early intervention services and other medical or community providers, and the rate of dual referrals varied widely by site (6% in Olmsted County to 52% in Ramsey County) (Figure 6).

Differences in the use of dual referrals at the clinic level can be explained by the wide range of referral practices followed by providers at each site. One provider, for example, stated that children with a suspected global developmental delay are referred to both early intervention and medical specialty services, while children with a single delay, such as a hearing concern, are usually referred to a single specialty provider. Other sites were much more concerned about the potential for duplication of services and preferred to make referrals to only one option (early intervention services or medical care) if a delay was identified. In addition to these differences in individual clinical practice, providers also used different types of referrals when mental health/social-emotional developmental concerns were identified. At three sites, providers tended to make referrals directly to a mental health professional if social-emotional development concerns were identified, rather than to early intervention services.

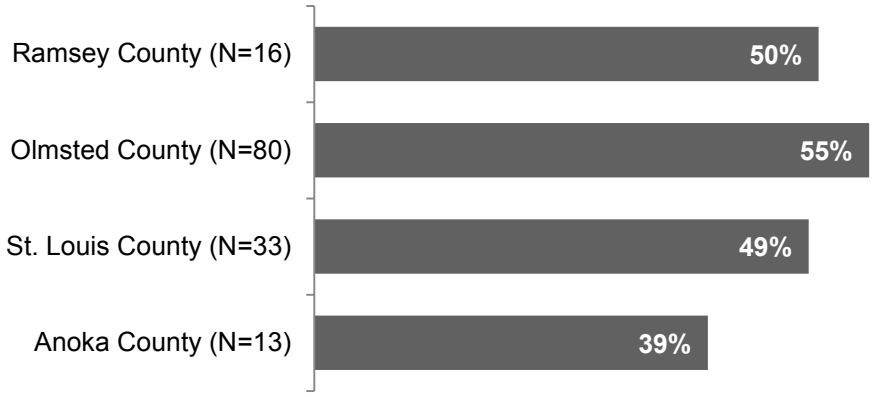
6. Referrals made to early intervention and medical/community providers

	Ramsey County	Olmsted County	St. Louis County	Anoka County	Combined
Number of referrals made to Help Me Grow	27	107	34	12	180
Percentage of children referred to Help Me Grow who had elevated screening scores	90%	100%	80%	25%	81%
Number of referrals made to medical providers or other agencies	15	5	68	5	93
Percentage of children with elevated screening scores referred to other services	56%	5%	45%	0%	42%
Number of dual referrals to early intervention and medical providers/ community organizations	14	5	12	5	36
Percentage of children referred to early intervention services also referred to medical providers/ community organizations	52%	6%	35%	42%	20%

Note: *The total number of children entered into the database includes only children in the site's target population (children age 0-5, MA-enrolled) who have elevated screening scores or who are referred to early intervention services.*

Clinic providers are making appropriate referrals to early intervention staff. Across all sites, early intervention staff felt that they were receiving appropriate referrals from their clinic partner. Some providers reported that, as a result of knowledge gained during the initiative, they were more likely to refer children at risk of a delay (e.g., premature babies). Because this project creates a feedback loop from early intervention services to primary care, the clinics now have quantifiable data about whether their referrals to early intervention services are appropriate. Overall, half (51%) of children ages 0-2 referred to early intervention services and for whom the clinic had heard back about, were determined to be eligible for Part C services (Figure 7). Because this information has not been shared with the clinic for all children, the percentage of children eligible for Part C may be much higher (up to 82% if all children with missing data were determined to be eligible for services). The fact that some children are found to be ineligible for services is appropriate, as it suggests providers are using screening results and information shared by parents to refer high-risk children for further assessment, rather than only those with an obvious delay or serious medical condition.

7. Percentage of children (ages 0-2) confirmed to be eligible for Part C early intervention services



Overall, a majority of parents received, and were pleased with, the advice they received from their provider in regard to screening results. Most parents (79-83%) were very satisfied with the way their child's doctor or provider handled that part of the visit (Figures 8,9).However, fewer parents reported that they received advice or plans for next steps from their clinic doctor or staff following a mental health screening, compared to after a developmental screening (51%, compared to 71% of parents).

Parent satisfaction with the way their child's provider addressed screening during their visit may be improving over time. Compared to 2011, a larger percentage of parents in 2012 reported that they were "very satisfied" with how their child's provider handled that part of the visit (Figures 8, 9). This finding could be the result of changes in practice among the participating clinics in how they talk to parents about screening results or make referrals. Provider champions from three of the participating clinics reported the screening and referral practices they had been using for this initiative had been adopted by their colleagues and two providers specifically noted they were using a more deliberate approach to discuss screening results with parents by the end of the initiative.

A larger percentage of parents reported their child was screened for a developmental concern in 2012 compared than baseline (71%, compared to 65% at baseline). However, parents were less likely to report their child received screening for a mental health concern (51% in 2012, compared to 56% at baseline). These results are inconsistent with the perspectives of clinic staff, who reported that both developmental and mental health screening practices were being used more consistently and by a larger group of providers at the end of the grant period. This difference may be due to differences in the ages of children whose parents were interviewed during the two data collection periods; most parents interviewed in 2012 (67%) had a child under the age of 2, compared to only half

of the parents interviewed at baseline. While the data from the parent interviews may align with self-reported changes in practice and suggest a promising trend, they should be interpreted with caution, as the response rate for the 2012 survey was lower than desired and small numbers of parents from each clinic responded to the question overall.

8. Parent perceptions of provider advice given and approach used following developmental screening or assessment

Percentage of parents who reported they:	Ramsey County (N=21)	Olmsted County (N=14)	St. Louis County (N=7)	Anoka County (N=15-16)	Total (N=69)*	2011 Baseline Total (N=106)*
Received advice or plans for next steps from clinic doctor or staff	67%	79%	5	70%	71%	65%
Felt "very satisfied" with the way child's doctor or health providers handled this part of the visit	86%	71%	6	85%	83%	80%

** Asked only of parent who reported their child received some type of screening or assessment in this area.*

Notes: *Feedback was gathered from a random sample of parents whose child (age 0-5) was screened at the clinic within the past 12 months. Different parent samples were drawn each year and it is not known how many parents may have responded to the interview at both time points. Percentages are not reported for sites with fewer than 10 parent respondents. The random sample for Anoka County includes patients seen by both clinics participating in the pilot study.*

9. Parent perceptions of provider advice given and approach used following mental health screening or assessment

Percentage of parents who reported they:	Ramsey County (N=11)	Olmsted County (N=9)	St. Louis County (N=6)	Anoka County (N=15-16)	Total (N=41-42)*	2011 Baseline Total (N=77)*
Received advice or plans for next steps from clinic doctor or staff	46%	6	2	53%	51%	56%
"Very satisfied" with the way child's doctor or health providers handled this part of visit	79%	7	5	81%	79%	72%

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

Notes: *Feedback was gathered from a random sample of parents whose child (age 0-5) was screened at the clinic within the past 12 months. Different parent samples were drawn each year and it is not known how many parents may have responded to the interview at both time points. Percentages are not reported for sites with fewer than 10 parent respondents. The random sample for Anoka County includes patients seen by both clinics participating in the pilot study.*

Key findings: Care coordination practices

> The worry I have is for those kids who the school district can't get a hold of or who decline services. If there is something else going on, you don't really know in a timely manner. —*Clinic care coordinator*

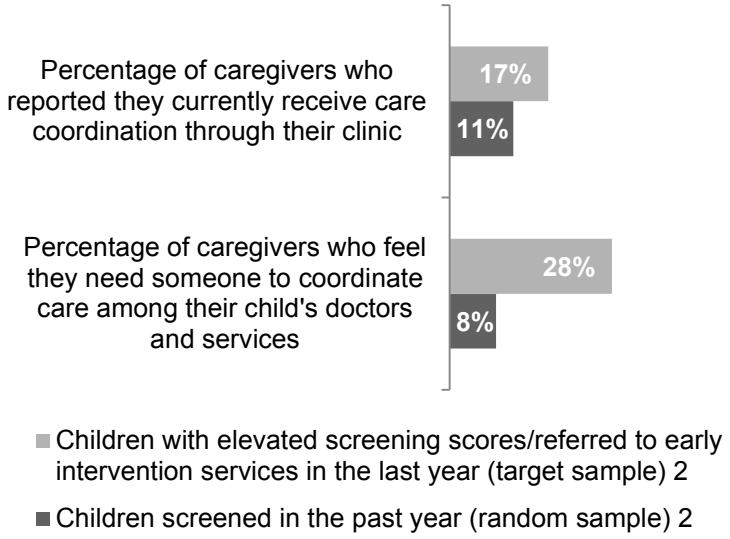
Care coordination practices also varied widely across sites. While the care coordinators at all participating clinics played a role in facilitating referrals to early intervention services and tracking communication back to the clinic, the degree to which they worked directly with parents to schedule appointments (i.e., provide active referrals) and the amount of time they spent following up with school districts following a referral varied. Again, there are a number of factors that contribute to these differences. The clinic care coordinators involved in this initiative had other roles and responsibilities within their clinic and some felt it was difficult to dedicate consistent time to the project, particularly given the small numbers of patients reached through this initiative. One clinic care coordinator noted that their well-child checks last an hour, longer than the time generally allotted by other clinic. As a result, the child's provider plays a more significant role in assisting with referrals and other activities that might otherwise be considered part of a care coordinator's responsibilities. Overall, there were differences among care coordinators in whether they took a more proactive role to encourage communication from school district staff or had a more passive approach, serving as a point person for paperwork rather than working to facilitate improved communication.

A challenge for care coordinators is determining when or how to respond when they don't hear information back about a child. It is important that informed consent forms are signed as soon as possible to allow school districts to share information with clinic staff. If the school district doesn't have a signed release of information form in place, clinic staff interested in the status of a referral cannot be sure whether the paperwork has been delayed or services have been refused. For care coordinators interested in playing more of a proactive role in follow up with families after a referral, this ambiguity makes it more difficult to determine when and how to respond.

Feedback from parents suggests that there is a need for more care coordination services to be made available. In the parent interview, care coordinators were described as clinic staff 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." Using this definition, 11 percent of parents in the random sample of patients screened in the past year and 17 percent of parents of children whose child had an elevated screen and/or were referred to early intervention services (the targeted sample) reported they were currently receiving care coordination through their child's clinic (Figure 10). However, some parents (8% of the random sample and 28% of

the targeted sample) felt they needed someone to help them coordinate their child's care and services. The use of and interest in care coordination services has not changed since the beginning of the grant period. At baseline (2011), 10 percent of parents reported they received care coordination services and 6 percent of parents reported they were interested in someone to help them coordinate their child's care. While the total number of parents who feel that more care coordination support would be beneficial may be small, this feedback from parents suggests care coordination is an ongoing unmet need.

10. Parent perceptions of care coordination services



Key findings: Communication practices

> The importance of having that communication with other providers in a child's life, it just really makes a difference if we're thinking of children that do have some extra needs. That circle of support that we can provide – this seems to do that. That's a positive thing. It reinforces that need to bring everyone on the team together to support the child. Sometimes what we hear at the school isn't the same story the doctor hears. When we all communicate the pictures comes full circle. *—Early childhood provider*

All pilot sites successfully worked around or worked through barriers to communicating information between clinics and schools, but did not eliminate these problems. At the beginning of the initiative, all pilot sites put considerable effort into developing shared release of information and communication forms that could be used by both clinic and early intervention staff to enhance communication. However, ongoing

confusion about competing data sharing requirements (HIPAA and FERPA[1]) and different preferences for the wording and content of release of information forms among various stakeholders made a shared form unrealistic to pursue a single statewide version of a shared release of information form. Instead, both clinics and school districts have made changes to their referral and intake protocols to better ensure that release of information forms are consistently signed by parents. While this step doesn't streamline paperwork for the family, the strategy has been successful in increasing communication between the clinic and early intervention services.

Clinic data suggests that consistency in communication can be improved. Because the timeline for school district staff to complete an assessment is shorter and more straight-forward for Part C services, we focused on the consistency and timeliness of communication for children ages 0-2 who were referred to early intervention services. Overall, 51 percent of children (ages 0-2) who were referred to early intervention services were found eligible for Part C services (Figure 11). However, that percentage may be much higher, as the eligibility status was unknown for nearly one-third (31%) of children referred. Olmsted County received feedback from school district staff for 80 percent of the children they referred, while the frequency of feedback was lowest for Anoka County (Figure 11).

11. Early intervention eligibility status, for children ages 0-2 referred to early intervention services

	Ramsey County (N=16)	Olmsted County (N=80)	St. Louis County (N=33)	Anoka County (N=13)	Combined (N=142)
Children eligible for early intervention services	8 (50%)	44 (55%)	16 (49%)	5 (39%)	72 (51%)
Children not eligible for early intervention services	2 (13%)	20 (25%)	3 (9%)	0 (0%)	25 (18%)
Eligibility status unknown	6 (38%)	16 (20%)	14 (42%)	8 (62%)	44 (31%)

Data reported by clinics suggests the timeliness of communication has improved over time. Federal Part C guidelines require early intervention staff to complete assessments for children ages 0-2 within 45 days of receiving a referral. With that timeframe in mind, timely communication back to the referring clinic would also occur in approximately 45 days. Overall, the median number of days between referral and receipt

[1] HIPAA refers to the Health Insurance Portability and Accountability Act, federal legislation that provides protections for personal health information collected by covered entities, including clinics. FERPA is the Family Educational Rights and Privacy Act, which provides federal protections for educational institutions to follow to protect the privacy of student educational data.

of follow up information ranged from 54 to 65 days for the four pilot sites (Figure 12). However, the amount of time between referral and follow up communication could be much longer; all sites reported at least one case where six months or longer passed before they received information from the child's school district. It is important to note that because delays in the assessment process can also be the result of parents refusing services or requesting a delay in the assessment timeframe, it is important for informed consent forms to be signed as early in the process as possible so that the teams know the causes of delays and can address them appropriately.

12. Average length of time (in days) between clinic referral and follow-up communication from early intervention services for children ages 0-2, by site

	Percentage of children referred with communication received from EI services	Average (mean)	Average (median)	Range
Ramsey County (N=16)	75%	107 days	65 days	2-433 days
Olmsted County (N=88)	84%	96 days	59 days	1-815 days
St. Louis County (N=33)	85%	71 days	60 days	20-187 days
Anoka County (N=11)	55%	88 days	54 days	8-188 days

Note: *This total includes all children referred to early intervention services, including those for whom the clinic has not received follow-up information.*

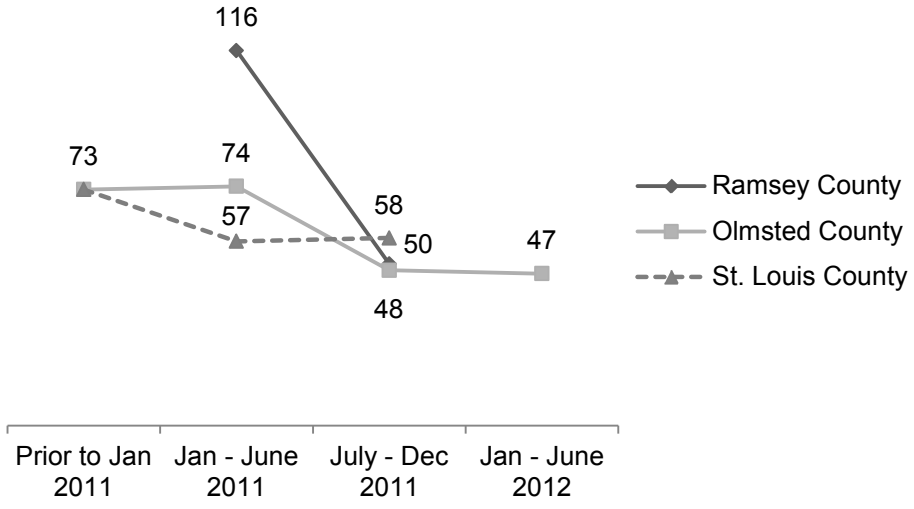
Preliminary data suggests that the timeliness of communication has improved over time. For each of the three pilot sites with sufficient data available, the timeliness of communication from early intervention staff improved during the last half of the initiative (Figures 13-14). While the median for each site shows that communication from early intervention services is approaching the ideal 45-day period (ranging from 47-58 days for each site's most recent data), communication for at least one child referred was not received until more than 3 months after the referral occurred. Again, these data should be considered preliminary, as there may be situations where the clinic is still waiting for communication regarding children referred to early intervention services in more recent months. However, these data align with the observations of the pilot site representatives who have described efforts to better identify children who have "fallen through the cracks" and to monitor the status of all referrals made/received. Additional data collection activities could also help identify factors that contribute to delays in communication for each pilot site, but were not part of the evaluation framework for this initiative.

13. Changes in average length of time (in days) between clinic referral and follow-up communication from early intervention services for children ages 0-2, by site

Number of children referred	Time period	Average (mean)	Average (median)	Range
Ramsey County				
7	Baseline: Jan 2011 – June 2011	139 days	116 days	2-433 days
4	July 2011 – Dec 2011	53 days	50 days	21-92 days
N/A	January 2012 or later	Insufficient data to report		
Olmsted County				
11	Baseline: Prior to January 2011	203 days	73 days	25-815 days
28	Jan 2011 – June 2011	109 days	74 days	10-336 days
18	July 2011 – Dec 2011	53 days	48 days	20-105 days
17	January 2012 or later	51 days	47 days	1-141 days
St. Louis County				
6	Prior to January 2011	98 days	73 days	20-187 days
11	Jan 2011 – June 2011	64 days	57 days	36-169 days
11	July 2011 – Dec 2011	63 days	58 days	29-105 days
N/A	January 2012 or later	Insufficient data to report		

Note: *This total includes all children referred to early intervention services, and for whom the clinic has received assessment results. Data from Anoka County are not included, as averages could not be calculated by time period with so few children being referred and inconsistent communication from early intervention staff.*

14. Changes in median length of time (in days) between clinic referral and follow-up communication from early intervention services for children ages 0-2, by site



Key lessons learned: Additional accomplishments, challenges

Pilot site teams reported that, as a result of the initiative, relationships improved and providers changed their referral practices. Improved relationships contributed to the success of each team in achieving the project's ultimate goal of improving communication between early intervention services and clinics. Through a survey of providers practicing at all participating clinics conducted at baseline, we learned that few providers felt they had a strong understanding of the early intervention services available to children or a strong working relationship with local early intervention staff. Although this survey was not repeated to assess changes over time, qualitative data collected throughout the project suggests that relationships and referral practices have changed over the life of the project. In interviews conducted near the end of the initiative, providers reported that they have a better sense of the services available through the local school district, as well as when to refer children. In addition, most of the team members involved in the initiative felt that their team had been successful in improving communication and relationships between clinics and school districts. Despite of all sites self-reporting these changes and self-reported spread in consistent screening and referral practices among their colleagues, the data submitted by each of the participating clinics doesn't show that the number of referrals made to early intervention services increased notably over time. This is surprising, given that clinic providers report that they feel they are more likely to occur children to early intervention services and that a larger number of clinic providers are involved with each project. It may be that some of these changes in practice were not captured through the evaluation, as data collection focused only on screening and referral practices for children insured through public health insurance programs, or that the baseline data was not a true reflection of referral practices prior to the start of the project.

Prior to the initiative, none of the teams had consistent processes in place to streamline referrals, share medical information with early intervention staff, or to communicate early intervention assessment results to the referring provider. The development of forms to share information across systems is a significant accomplishment for all pilot site teams who participated in the initiative. However, more work is needed to ensure the forms are consistently used by early intervention/school district staff, particularly as teams work to sustain and expand their work into other districts and clinics.

For most teams, face to face meetings were considered to be an essential step for building relationships across systems. Although pilot team members recognized the challenges of taking time away from their regular job roles and responsibilities to participate in team meetings, most felt the face to face contact that occurred during meetings helped to improve relationships and allowed them to discuss potential solutions to observed challenges. In addition, some team members noted that meetings provided

them with new information about the services available to young children and strengthened their understanding of the approach taken by other systems to assess and respond to the needs of children. Teams who saw value in these meetings were concerned about how to sustain them without the financial incentive provided with this project and how to keep the number of meetings manageable as they work to bring new partners into their work.

The long time period early intervention staff are allowed in order to complete an assessment for children ages 3-5 is understood by clinic staff, but is less than desirable. For children birth to 3 years of age, early intervention staff have 45 days to complete the assessment used to determine eligibility for services and an appropriate service plan. The process can take much longer for older children (ages 3-5), as the timeline does not include non-school days. Clinic representatives understand that different processes influence the overall time needed to complete the assessment, but also noted that those types of delays would not be acceptable if they were making a referral to another medical provider. In addition, the long delay is a challenge for care coordinators trying to work more proactively to follow up on referrals made to early intervention services.

Throughout the course of the initiative, the most significant challenges teams faced were issues related to release of information forms and data sharing across systems. For all teams, a major project goal was to streamline communication between early intervention and clinic staff. Ideally, teams hoped that state agencies would develop a single shared release of information form that would allow information to be shared by both clinic and early intervention staff and would have to be completed only once by the parent. None of the teams were successful in developing that type of form. However, the teams did develop forms and processes to communicate information after appropriate consent forms were signed. All sites hoped for more guidance from state agencies in order to develop a form that could be used consistently across school districts and clinics. Teams anticipate that the lack of consistency across districts and clinics will be a barrier to spread and sustainability.

Enhancing current efforts: Promoting sustainability and spread

As briefly described earlier in the site-specific summaries, all pilot sites have already begun to take steps to expand their efforts to include multiple providers at the partner clinic, and some pilot sites are considering ways to expand these efforts to other departments, clinics, or school districts.

Current spread and sustainability efforts among pilot sites

> Find your advocates. Who are the players on both sides that want to talk and want to communicate? Make your list of people who work with young children and who might have an investment in making sure that kids do well. Find out who those advocates are, and engage them. —*Early childhood provider*

Across all participating clinics, the consistent use of screening tools and new informed consent and referral forms has spread. At each clinic, the initiative began with the involvement of a single provider champion who was interested in and willing to pilot new strategies to establish or enhance screening, referral, and communication processes. This work has spread to multiple providers within each clinic, and some pilot sites are also discussing other strategies to incorporate these forms and procedures into practice across other physician disciplines (e.g., family medicine), clinics within their health care system, or other clinics in the region. The strategies used by the pilot clinics to encourage spread have varied, from peer-to-peer sharing among providers to administrative decisions to establishing new practice standards that providers are expected to follow. The pilot project demonstrated that the development of streamlined paperwork is critical for sustainability. After the communication tools were in place, clinics were able to use the dissemination strategies that work best within their clinic culture to encourage spread and sustainability.

All teams have also made efforts to expand their work into new clinics or school districts. While all pilot sites have engaged new stakeholders in their work, some teams noted that it took longer and required more effort than anticipated to encourage new clinics or school districts to become involved in the initiative. Opportunities to share information about the processes the pilot site has developed and to encourage other partners to adopt these practices has occurred primarily through establishing personal relationships with key stakeholders of other clinics and school districts. Some pilot sites have also made very intentional efforts to build stronger relationships between clinics, school districts, and other child-serving agencies, such as local public health departments or Head Start.

While some clinics found elements of the Access database helpful for care coordination purposes, none of the sites have definite plans to continue using that tool after the initiative ends. The Access database developed by DHS includes a number of reporting options that care coordinators can use to identify which children have been referred and whether follow-up communication has been received from the school district. However, for the database to operate optimally as a comprehensive care coordination tool, clinic staff must enter patient information, screening results, and other information into both their clinic EMR system and the Access database tool. Duplicate data entry is a significant burden for clinic staff. While the database may not be a long-term solution for clinics, it may be useful for clinics to use when piloting new screening, referral, and communication processes. As these processes are formalized, clinics could consider the feasibility of integrating some key features of the Access database into their EMR system.

Information and technical assistance will continue to be available through the state's Department of Human Services. Lessons learned from the ABCD III project will be used further enhance state's quality improvement project, Communities Coordinating for Healthy Development (CCHD). A toolkit and other resources have been developed and are available online to help other clinics and school districts learn how they can adopt improved referral, communication, feedback, and coordination practice strategies into their work. DHS and MDE are discussing ways to allocate staffing resources to support ongoing work to present information about this initiative, meet with interested school districts and clinics, and provide technical assistance to those working to embed new practices into their work.

Additional opportunities for spread and sustainability

There are opportunities for state agencies to encourage improved referral, communication, and coordination practices. Although the work done by the pilot sites has shown that gains can be made when individuals become heavily engaged and invested in encouraging changes in practice, all pilot teams felt that greater support and guidance from the state level was needed to encourage spread and sustainability. In addition to maintaining funding for staff to provide outreach and technical assistance, the practices adopted by clinics, school districts, and other early intervention staff could be supported and encouraged most directly as new Health Care Home certification requirements are developed for pediatric patients. In addition, efforts could be made to share information about CCHD to stakeholders involved with other early childhood initiatives supported by DHS. The state's Department of Education (MDE) also has opportunities to support increased care coordination and communication strategies in through their Race to the Top project, as well as ongoing training to early intervention staff.

Issues to consider when promoting sustainability and spread

Buy-in at multiple levels within clinics, school districts, and community agencies, as well as at the state policy level, is essential to sustain changes in practice over time. Much of the initial work done by the ABCD III pilot sites focused on individual changes in referral, coordination, and communication practices. However, as their work began to expand to focus on adoption of these practices among other colleagues, different stakeholder buy-in is needed to support these efforts and formalize changes in practice. In general, pilot sites that had more centralized responsibility for reporting information back to the referring clinic seemed to provide more consistent feedback than models with more diffused responsibility. While this doesn't necessarily imply that an ideal practice model must include a role for a single person to coordinate communication, it does suggest that different stakeholders, such as team leads or staff supervisors, may need to be engaged in project planning and in conversations about the project and its spread. Job descriptions and staff responsibilities may need to be redefined to explicitly include new referral, coordination, and communication activities.

Patience and persistence will be needed to expand each pilot project into new school districts and clinics. Based on the feedback gathered from stakeholders during the key informant interviews, spread was more challenging and time-consuming than they had anticipated. Progress in this area is being made by some sites, but only as a result of very deliberate efforts to engage other stakeholders in discussions around the project. In addition, there number of clinics and school districts who participated in the pilot study have decided that they will use the same processes to obtain a signed release of information form from parents, share appropriate screening and assessment data, request information, or send assessment results for all children served, regardless of their insurance status, school, or provider. Staff who are adopting these changes may feel frustrated if it seems that their extra efforts are going unnoticed, and so patience will be needed as new partners become involved in this work.

Spread can, and will likely need to, be supported at both a local level and state level. Across the state, there are nearly 500 school districts, most with their own early childhood staff member(s) responsible for conducting assessments and developing individual treatment plans. However, communicating assessment results and other information back to the referring clinics has not been part of their job responsibilities. In order for spread of these enhanced communication and coordination practices to occur in school districts throughout the state, buy-in is needed at multiple levels. Efforts have been made by both pilot sites and DHS staff to share information about the ABCD III initiative with other school districts and clinics interested in improving their care coordination practices. However, state agencies play a key role in supporting changes in practice through the training and other guidance they offer to school districts, regional Interagency Early Intervention Committees (IEICs),

and medical providers, as well as the ways they incent and encourage screening, referral, care coordination, and communication activities through changes in reimbursement policy and future funding opportunities. The potential role professional groups may have in promoting changes in practice or creating forums to allow for peer sharing of best practices were not discussed by the pilot partners, but may be helpful to consider.

Some standardization of paperwork would likely aid spread and sustainability efforts, but may be difficult to achieve. As members of each pilot site have worked to engage other school districts, clinics, or community partners in their work, modifications to the referral and communication forms have been made to accommodate the unique preferences and practices of new partners. However, this approach means that there is a risk that a different version of each form will be created for each partner, complicating paperwork for all involved in the initiative. DHS has developed a common referral and communication form that can be used to share information between clinics and school districts but there is no requirement that all communities use a common form to share information. However, teams should consider the advantages and disadvantages of accommodating the unique requests made by new partners with their interests for long-term efficiency.

The state's online Help Me Grow referral system provides an opportunity to better facilitate communication and new relationships between referring providers and school district staff. As suggested in past reports, clinics are very interested in receiving some type of message from the online referral system that confirms a referral has been receives and provides the clinic with contact information for the staff person who can be reached for more information. One clinic coordinator suggested even having a list of key contacts for all local school districts would help increase their efficiency and give the clinic a place to start when seeking follow-up information from a school district.

Guidance from state agencies is needed to clarify the informed consent and data sharing practices that school districts and clinics can pursue. As mentioned throughout this report, the most significant barrier identified by the pilot sites has been issues around data sharing and releases of information. Although decisions around forms and processes may still be made ultimately at the local level, clearer guidance from state agencies may help clinics and early intervention staff develop informed consent and communication forms more quickly and with greater consistency.

Moving forward: Conclusions and recommendations

Overall, the ABCD III initiative led to the development of new screening, referral, and communication strategies in four counties across the state that can be sustained and expanded over time. However, this initiative also demonstrated that there are many barriers to improving communication and coordination across child-serving systems, including some that have been addressed and others that require ongoing attention. The recommendations offered address key barriers that arose during the ABCD III initiative. The CCHD toolkit developed by DHS also provides recommendations for how to address challenges to implementation.[2]

Suggested enhancements for pilot partners

- **Continue monitoring the status of referrals and develop internal processes to ensure follow-up communication occurs.** It is tempting at the end of an initiative to discontinue various data collection activities in an effort to reduce time spent on paperwork. However, the experiences of the pilot sites highlighted the importance of proactive communication and follow-up to determine the status of children referred to early intervention services. Both clinic and early intervention staff are encouraged to maintain or create new monitoring processes to help ensure consistency in follow-up and to aid ongoing quality improvement efforts.

- **Engage parents in deliberate discussions around social emotional development and mental health.** Parent satisfaction with the screening process and advice or suggestions for referrals offered by providers was lower for parents whose children had been screened for potential social emotional developmental concerns, compared to those whose children were screened for potential physical/cognitive developmental concerns. Additional exploration of this issue is needed to determine the reasons for these differences. It may be that providers are less comfortable talking about early childhood mental health issues or that they language they use around social emotional development does not resonate with parents as a unique aspect of childhood development. Providers may need to reassess the language they use when reviewing these screening results with parents and also more deliberate in discussing parent concerns about their child's behavior.

[2] The CCHD toolkit is available online at: https://edocs.dhs.state.mn.us/lfserver/Public/DHS-6538-ENG

- **Use concerted efforts to connect with local early childhood mental health providers on a regular basis.** Interviews with team members from each pilot site demonstrated that providers used very different approaches when making referrals for early childhood mental health services in their communities. For example, one provider referred almost exclusively to medical specialists within their provider network with others directed most of their referrals through the early intervention system. One site also pointed out that they commonly make referrals to the county's crisis response center, as a result of the limited availability of mental health services in their community. Given the need for early childhood mental health services, it is critical for clinic and early intervention staff to work deliberately to build relationships with local providers in order to ensure they have appropriate referral options available and are able to accurately identify gaps in services.

- **Work to build relationships with clinic, school districts, and community agencies that are not currently involved in the initiative.** Pilot sites that were successful in engaging new partners into their work found face-to-face meetings were essential to share information about the initiative and to identify opportunities for collaboration. Written information about the initiative can be a helpful tool in increasing knowledge, but likely needs to be part of a more direct strategy of meeting with potential partners if spread is to occur.

- **Consider ways to integrate ABCD III initiative activities into the job descriptions of involved staff and allocate time and resources to support care coordination and communication activities.** Across all sites, many of the team accomplishments can be attributed to the efforts of key staff who have "championed" this work, often taking on tasks that are above and beyond their typical job descriptions to improve communication and coordination across systems. Without formalizing these activities and having strategies in place to train in new staff, staff turnover can disrupt referral, communication, and coordination efforts. In addition to continuing their work to create written documents describing their processes, responsibilities may need to be added to current job descriptions to help ensure the work can be sustained through changes in staffing. Staff time and other resource allocations (e.g., modifications to existing tracking systems to monitor the status of referrals) may also be changed in order for these efforts to be sustained over time. Partners may need to do more work within their clinic, school district, or agency to create buy-in for these changes at multiple administrative levels.

Suggested enhancements for state-level stakeholders

- **Identify opportunities to reinforce changes in practice through larger statewide initiatives and be explicit in articulating these connections to clinics, school districts, and community organizations working to improve coordination around early intervention services.** There are a number of broader initiatives occurring across key state agencies (Departments of Health, Human Services and Education) that have some emphasis on improving screening and referral practices, enhancing care coordination services, identifying children with potential developmental concerns as early as possible, and enhancing cross-system communication. This presents an opportunity to share information about the ABCD III initiative with new audiences and describe how the Coordinating Communities for Health Development (CCHD) initiative aligns with other efforts to improve the quality of services. Direct communication to the pilot sites and other communities that are engaged in efforts to improve communication and coordination across child-serving systems that explicitly describes how their work ties into these larger efforts can help local partners work strategically to expand their work and better leverage new resources.

- **Implement enhancements to the online Help Me Grow system that help facilitate communication between clinic providers and school district staff.** The pilot site teams have continued to suggest a number of enhancements to the Help Me Grow referral system that would help them better monitor the status of referrals they make to early intervention services: an option to attach documents to allow for sharing of screening results, referral forms, and other medical information; and a system confirmation email that assures the provider the referral has been received and includes the contact information for the school district staff members who they can contact for additional information.

- **Encourage the use of best/promising practices in communication and care coordination through trainings provided to staff, the development of new policy guidelines, and reimbursement incentives.** State agencies also have opportunities to encourage changes in practice that improve referrals, communication, and coordination through trainings they provide to relevant audiences and the development of new policies. The Health Care Home certification process, for example, may present an opportunity to introduce best practices around care coordination and shape expectations for increasing communication across systems. School district staff could be required to meet with local clinics annually to build relationships and to discuss ways to improve current screening, referral, and communication activities as a Child Find strategy.

- **Coordinate across agencies to provide clear guidelines around data sharing practices.** Because data privacy is a concern of all agencies and pilot team members, a major goal for the initiative was to create consistent data sharing forms and procedures that can improve communication and coordination between schools and medical providers. Although all pilot teams were able create forms and processes to share information, the initiative fell short of developing a universal system that was endorsed at the state-level and encouraged to be used consistently by clinics and schools. Throughout the initiative, the pilot sites have asked for clearer guidelines around data sharing practices and leadership at the state level to promote the use of common forms and processes. Continued work towards this end would help support sustainability and spread efforts, as there is concern that communication will become too burdensome if all new school and clinic partners develop individualized versions of release of information and communication forms.

Appendix

Data collection tools

Care coordinator interview protocol

Provider champion interview protocol

Early intervention staff interview protocol

Parent interview protocol

Summary of key reporting measures

ABCD-III (Assuring Better Child Development)
Care Coordinator Interview

NAME OF CLINICS: Fridley Children's, Mayo Pediatrics, Rochester, Saint Luke's Pediatric Associates, Duluth, and Health Partners, White Bear Lake

This is __[Interviewer]__ calling from Wilder Research. As you know, we are working with the Minnesota Department of Human Services on the evaluation of the ABCD III Initiative. We are doing our final round of interviews with representatives from each pilot site to identify promising practices, lessons learned, and strategies for sustainability.

Some of the questions I'll ask you about today are similar to things we discussed before. However, some of what I will ask is focused on sustainability and documenting the changes you have made over the past few months.

This interview will last no more than an hour. Do you have any questions for me before we begin?

First, I would like to ask you a few questions about your work as a care coordinator and your role in the ABCD III Initiative:

1. Has your role with the initiative changed over the past year? *What are your current roles and responsibilities as care coordinator?*
2. Care coordination involves managing information that leaves and comes to the clinic. However, that can range from simply being the point person at the clinic to proactively following up on patient needs. With that distinction in mind, could you describe how involved you are in monitoring feedback from referrals and seeking information from community and early intervention referral partners?
3. When you receive information from local school district or other early intervention services, what do you do with that information? How is it shared with the provider?
4. Overall, approximately how many hours per week approximately do you and others in your clinic spend on care coordination duties/activities? Is this the right amount of time?
5. If you could think about ideal care coordination, without worrying about funding the position or staff time, what would it look like at your clinic for children age 0-5?

TRACKING: I have a few questions about how you are using the Access database now, and whether you plan to use it in the future.

6. All clinics are using the database to enter evaluation information for all children 0-5 who have elevated screens and all who are referred to Help Me Grow. Are you using the Access database to enter more than those requirements?
   If YES → What additional information are you entering?
7. Are you using any other systems to track screened and referred patients <u>in addition</u> to the Access Database?
   If YES → Can you describe that system/tool/database? To coordinate care, which system/tool/database do you use?
8. Do you plan to continue using the Access Database [or other primary care coordination tool] moving forward?

If NO → What tools will you need to coordinate and monitor care? Do you have plans to have those tools in place by the end of ABCD III?

THE REFERRAL PROCESS. I'd like to shift gears to talk specifically about the process you use to make referrals to Help Me Grow, community agencies, mental health providers and medical specialists. I'd like you think primarily about the steps that now occur when a patient at your clinic needs a referral.

REFERRALS TO HELP ME GROW:

7. To begin, I'd like to walk through the intake, assessment, and referral process you would use for a referral that came to you today. [NOTE: Send copy of flow chart to interviewee to review and refer to during the call] This flow chart was developed last year to reflect the referral and communication processes used by your team.
    a. Does this flow chart accurately describe what your referral and communication processes looked like a year ago?
        If NO → What changes should be made to the flow chart? [Use probes to make relevant changes to the diagram.]
    b. Does this [revised] flow chart still describe the referral and communication processes in place today?
        If NO → What changes were made? Why did this change take place?
    c. Is the same process used for developmental, mental health, and specialty medical care referrals and communication?
        If NO → Can you describe those referrals and communication pathways? [How should those processes be integrated into this flow chart?] Why is a different process used for these types of referrals?
    d. Looking at the flow chart, are there any pathways where communication may not happen consistently or the process does work as well as you would like?
        If YES → What are those pathways? What do you see as the barriers to [better communication]? Do these barriers persist across all ages (0-5) and cultural groups, or is this an issue that seems to impact a certain demographic? How have you tried to address these issues?
    e. If you were not restrained to think about funding or other resources, are there any changes you would like to make to this process?
        If YES → What are those changes you would like to see? Is there anything that keep you from making those changes now?
    f. Do you think these processes can work well for other clinic and school district partnerships interested in enhancing their referrals and communication?
        If YES → Are there any pieces in particularly that you feel are particularly useful in enhancing communication?
        If NO → What would keep other sites from adopting your model?

REFERRALS TO COMMUNITY AGENCIES:

9. Does your clinic **actively** [an active referral means that someone at the clinic is making the referral for the family/patient rather than giving them the information to make their own referral (passive)] refer to any community agencies or resources, such as public health, Head Start, ECFE, or food shelves?

    If YES → What does that referral process look like? Do you request any information back or follow up with the parent?

If NO → Why doesn't your clinic make referrals to these types of agencies? Do you feel this is something that your clinic should consider doing in the future? [Why or why not?]

10. Have you had any situations where you referred a family to Help Me Grow, but learned they didn't quality for services or that the family refused those services? What clinic services/referrals do you/would you offer to families who learn they don't qualify for Help Me Grow?

FAMILY SUPPORT. We are also interested in lessons learned about supporting families through the referral process.

11. What have you learned about the best ways to talk to families about the services that may be available to them?
12. What are the most common concerns that parents have when their child has an elevated screen or when they receive a referral for services?
13. Are there additional things that you would like to do or like to see happen in order to better support parents throughout this process?

COMMUNICATION. We are interested in learning more about your clinic's levels of communication with Help Me Grow.

14. What barriers make it difficult to communicate effectively with schools/Help Me Grow staff*? What have you already done to address these challenges? Are there other ways you plan to address these barriers?*
15. What steps have you and/or clinic staff taken to improve communication between schools/Help Me Grow and your clinic? [Ask for copies of any forms that have been developed.]
16. What changes would you like to see to improve communication?

CARE PLANS. The care plan is a written summary document combining the needs, concerns and desired outcomes of the patient, family and care team in addition to the medical treatment plan. The care plan also outlines the services that will be provided to the family to meet their identified needs. The care plan is detailed to allow for follow-up and tracking by care coordinators.

17. Is your clinic currently using Care plans? [*If no, why not? Plans to use in future?]*
18. If yes, for whom are the care plans used? *[e.g. ABCD III patients only? Everyone in the clinic? Health Care Home patients only? Etc]*
    If using Care Plans, do you also use them for ABCD III patients?

SUSTAINABILITY. I'm also interested in hearing your overall thoughts about your involvement in this initiative, as well as sustainability and spread of the model to other clinic-school district teams.

19. What changes in practice do you think are most important for you to sustain after the ABCD IIII project ends? Have you already begun to consider how to sustain the changes you've made to improve communication and coordination with the clinic after the initiative ends? [If so, please describe your plans to continue this work after the initiative ends. What support is needed from the school, district, and/or State to help you sustain this work?]

20. What pieces of this initiative are not currently sustainable? What do you see as the most important challenges to sustainability?
21. Have you considered any steps to expand the changes you've made to your work with other schools? [If so, please describe changes. If not – why?] What pieces of this initiative are not currently sustainable? What do you see has the most important challenges to sustainability? [Probe to understand specific activities that are perceived as difficult to sustain and why.]
22. What work, if any, have you done to expand this initiative?

OVERALL

23. Overall, how would you rate your success in…
    a. Developing a model that improves communication between primary care clinics and school districts?
    b. Improving relationships between primary care and school district staff?
    c. Better ensuring young children receive appropriate early childhood services, as needed?
    d. Developing a plan to sustain your work after ABCD III ends?

    Would you say you were very successful, somewhat successful, somewhat unsuccessful, very unsuccessful, or that you had mixed results?

    For each item: Why did you choose that option? Can you give me an example that illustrates that?

24. What are the most important things you've learned through this initiative?
25. What advice would you give to other clinics interested in improving their communication/coordination practices with early intervention services programs and staff?
26. What do you see as the most important things DHS can do to encourage spread and sustainability of this initiative? MDE? Other state agencies or professional organizations?

ABCD-III (Assuring Better Child Development)
Clinic Champion Interview

This is __[Interviewer]__ calling from Wilder Research. As you know, we are working with the Minnesota Department of Human Services on the evaluation of the ABCD III Initiative. We are doing our final round of interviews with representatives from each pilot site to identify promising practices, lessons learned, and strategies for sustainability.

Some of the questions I'll ask you about today are similar to things we discussed before. However, some of what I will ask is focused on sustainability and documenting the changes you have made over the past few months.

This interview will last no more than an hour. Do you have any questions for me before we begin?

First, we would like to ask you a few questions about who you are and the work that you do at Clinic:

1. During the past year, has your role with the initiative changed in any way? [If so, please describe.]

REFERRALS
I'd like to begin review the processes you use to make referrals to Help Me Grow, community agencies, mental health providers and medical specialists.

2. I sent you a copy of the referral and communication flowchart we developed, based on conversations with you and other team members last year. Does this reflect how referrals and communication occurs right now? What types of changes have occurred?

3. Do you ever make dual referrals [e.g. to both Help Me Grow and another medical provider such as a specialist]?
   If YES → Under what circumstances?
   If NO → Why not?

4. If you identify potential social-emotional concerns for a child age 0-5, do you typically refer that child to Help Me Grow?
   If NO → Can you describe what you typically do in that situation?

5. Do you make any active referrals to other early childhood community resources or services, such as public health, ECFE, or Head Start?

6. Do you feel your referral practices have changed in any way since you began to be involved with the ABCD III initiative?

COMMUNICATION
Now I'd like to ask you a few questions that focus specifically on communication and coordination between your clinic and Help Me Grow and local school early intervention staff. I'd like you to think about both the information you send and receive, as well as the ways you work in partnership to coordinate services.

7. Please briefly describe the types of information you are receiving back from Help Me Grow or local schools once the referral and assessment have been completed. Are you notified when you get information back from a school district about one of your patients? Have you found that information useful in informing the care you provide? [Why or why not?]

8. What barriers make it difficult to communicate effectively with clinic providers/across systems? *[NOTE: This includes communication to and from HMG]* What have you already done to address these challenges? Are there other ways you plan to address these barriers?

9. What steps have you and/or clinic staff taken to improve communication between Help Me Grow and the clinic? Have you developed a process/protocol for providing feedback or communicating with the clinic?

10. In addition to the steps you've taken to improve communication with the clinic, are there steps you've taken to improve service coordination with the clinic? [If so, please describe.] How do you involve youth and families in service coordination and communication with the clinic? How do you see your care coordination role as similar to or different than the role clinic care coordinators play when working with children and families?

FAMILY SUPPORT.

We are also interested in lessons learned about supporting families through the referral process.

11. What have you learned about the best ways to talk to families about the services that may be available to them?
12. What are the most common concerns that parents have when their child has an elevated screen or when they receive a referral for services?
13. Are there additional things that you would like to do or like to see happen in order to better support parents throughout this process?

SUSTAINABILITY

14. Have any of your colleagues begun to adopt the screening, referral, and communication processes you've developed through this initiative? How did this spread occur? What do you see as challenges to spread within your clinic?

15. Have you done any work to spread this initiative into other practice areas or other clinics? How did this spread occur? What do you see as challenges to spread within your clinic?

16. Do you plan to sustain all or some of the practice changes you've made after the initiative ends? If not, why not?

17. What pieces of this initiative are not currently sustainable? What do you see as the most important challenges to sustainability?

OVERALL

We are also interested in your overall thoughts about your involvement in this initiative.

18. Overall, how would you rate your success in…
    a. Developing a model that improves communication between primary care clinics and school districts?
    b. Improving relationships between primary care and school district staff?
    c. Better ensuring young children receive appropriate early childhood services, as needed?
    d. Developing a plan to sustain your work after ABCD III ends?

    Would you say you were very successful, somewhat successful, somewhat unsuccessful, very unsuccessful, or that you had mixed results?

    For each item: Why did you choose that option? Can you give me an example that illustrates that?

19. Do you feel that implementing ABCD III has been beneficial to your clinic as a whole? (If so, how? If not, why not?)

20. Do you currently see spread of these activities happening in your clinic? [If NO, do you have any ideas for how it will happen in the future?] What will the barriers or challenges be?

21. What advice would you give to other clinics/practices like yours who are interested in improving their communication/coordination practices with Help Me Grow, mental health and other community agencies?

22. Have you shared what you have learned about the ABCD III Initiative with your colleagues?

23. Do you feel that other primary care providers in your clinic are interested in implementing practices from the ABCD III Initiative? Which practices?

24. Have other providers in your clinic started to implement practices from the ABCD III initiative?
If YES → How many? How many other providers, who have not adopted these approaches, practice in your clinic?

25. What are the most important things you've learned thus far through this initiative? (e.g. What do you see as your major accomplishments? Major barriers?)

26. What do you see as the most important things DHS can do to encourage spread and sustainability of this initiative? MDE? Other state agencies or professional organizations?

ABCD-III (Assuring Better Child Development)
Early Intervention Staff Interview

This is __[Interviewer]__ calling from Wilder Research. As you know, we are working with the Minnesota Department of Human Services on the evaluation of the ABCD III Initiative. We are doing our final round of interviews with representatives from each pilot site to identify promising practices, lessons learned, and strategies for sustainability.

Some of the questions I'll ask you about today are similar to things we discussed before. However, some of what I will ask is focused on sustainability and documenting the changes you have made over the past few months.

This interview will last no more than an hour. Do you have any questions for me before we begin?

First, I would like to ask you a couple questions about your background and your role in the ABCD III Initiative:

1. Right now, what is the role you play when referrals are made to Help Me Grow/the school? [Is that the same as the role you have had in the past?]
2. Can you describe the roles and responsibilities of anyone else from your office/school and affiliates who work on this initiative?

REFERRAL AND COMMUNICATION PROCESSES

3. To begin, I'd like to walk through the intake, assessment, and referral process you would use for a referral that came to you today. [NOTE: Send copy of flow chart to interviewee to review and refer to during the call] This flow chart was developed last year to reflect the referral and communication processes used by your team.
    a. Does this flow chart accurately describe what your referral and communication processes looked like a year ago?
        If NO → What changes should be made to the flow chart? [Use probes to make relevant changes to the diagram.]
    b. Does this [revised] flow chart still describe the referral and communication processes in place today?
        If NO → What changes were made? Why did this change take place?
    c. Is the same process used for developmental, mental health, and specialty medical care referrals and communication?
        If NO → Can you describe those referrals and communication pathways? [How should those processes be integrated into this flow chart?] Why is a different process used for these types of referrals?
    d. How are local EI staff involved in these referral and communication processes?
    e. Looking at the flow chart, are there any pathways where communication may not happen consistently or the process does work as well as you would like?
        If YES → What are those pathways? What do you see as the barriers to [better communication]? Do these barriers persist across all ages (0-5) and cultural groups, or is this an issue that seems to impact a certain demographic? How have you tried to address these issues?

f. If you were not restrained to think about funding or other resources, are there any changes you would like to make to this process?
   If YES → What are those changes you would like to see? Is there anything that keep you from making those changes now?
g. Do you think these processes can work well for other clinic and school district partnerships interested in enhancing their referrals and communication?
   If YES → Are there any pieces in particularly that you feel are particularly useful in enhancing communication?
   If NO → What would keep other sites from adopting your model?

4. Overall, do you feel like you are currently receiving appropriate referrals from the clinic? *[Probes: Are children being referred as early as they should be? Are you receiving the number of referrals that you would expect for children birth to five? Do you have thoughts about reasons clinics may not be referring children?]* Are there any steps you have taken to work with clinics to ensure you receive appropriate referrals? *[If so, please describe.]*

COMMUNICATION AND COORDINATION WITH CLINIC

Now I'd like to ask you a few questions that focus specifically on communication and coordination between your agency and the clinic. I'd like you to think about both the information you receive, the ways you communicate with the clinic, and the ways you work in partnership with the clinic to coordinate services.

5. What barriers make it difficult to communicate effectively with clinic providers/across systems? *[NOTE: This includes communication to and from HMG] What have you already done to address these challenges? Are there other ways you plan to address these barriers?*

6. What steps have you and/or clinic staff taken to improve communication between Help Me Grow and the clinic? Have you developed a process/protocol for providing feedback or communicating with the clinic? [Ask for copies of any forms that have been developed/copies of protocols.]

7. In addition to the steps you've taken to improve communication with the clinic, are there steps you've taken to improve service coordination with the clinic? [If so, please describe.] How do you involve youth and families in service coordination and communication with the clinic? How do you see your care coordination role as similar to or different than the role clinic care coordinators play when working with children and families?

FAMILY SUPPORT.

We are also interested in lessons learned about supporting families through the referral process.

12. What have you learned about the best ways to talk to families about the services that may be available to them?
13. What are the most common concerns that parents have when their child has an elevated screen or when they receive a referral for services?
14. Are there additional things that you would like to do or like to see happen in order to better support parents throughout this process?

SUSTAINABILITY

I'm also interested in hearing your overall thoughts about your involvement in this initiative, as well as sustainability and spread of the model to other clinic-school district teams.

15. What changes in practice do you think are most important for you to sustain after the ABCD IIII project ends? Have you already begun to consider how to sustain the changes you've made to improve communication and coordination with the clinic after the initiative ends? [If so, please describe your plans to continue this work after the initiative ends. What support is needed from the school, district, and/or State to help you sustain this work?]

16. What pieces of this initiative are not currently sustainable? What do you see as the most important challenges to sustainability?

17. Have you considered any steps to expand the changes you've made to your work with other clinics? [If so, please describe changes. If not – why?] What pieces of this initiative are not currently sustainable? What do you see has the most important challenges to sustainability? [Probe to understand specific activities that are perceived as difficult to sustain and why.]

18. What work have you done to expand this initiative across the school/school district?

OVERALL

19. Overall, how would you rate your success in…
    a. Developing a model that improves communication between primary care clinics and school districts?
    b. Improving relationships between primary care and school district staff?
    c. Better ensuring young children receive appropriate early childhood services, as needed?
    d. Developing a plan to sustain your work after ABCD III ends?

    Would you say you were very successful, somewhat successful, somewhat unsuccessful, very unsuccessful, or that you had mixed results?

    For each item: Why did you choose that option? Can you give me an example that illustrates that?

20. What are the most important things you've learned through this initiative? [Probes: What do you see as your major accomplishments/barriers?]

21. What advice would you give to other Help Me Grow regions interested in improving their communication/coordination practices with medical providers?

22. What do you see as the most important things DHS can do to encourage spread and sustainability of this initiative? MDE? Other state agencies or professional organizations?

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

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 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

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
Refused ..... (GO TO Q. 5a) 7
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 (18 months for "Targeted sample"), how many times was [CHILD'S NAME] seen at [NAME OF CLINIC]? Would you say…

1 time, ... 1
2 or 3 times, ... 2
4 to10 times, or 3
More than 10 times? 4
Refused 7
Don't know 8

5b. How may of these visits, during the past 12 months (18 months for "Targeted sample"), were your child's regular check-up or well-child visit? Would you say…

None, ... 1
1, ... 2
2 or 3, or 3
4 or more check-ups or well child visits? 4
Refused 7
Don't know 8

These next questions are related to your child's growth and development. Later, we will ask you some questions about emotional and mental health.

6. In the past 12 months (18 months for "Targeted sample"), 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

Next, we are going to ask some questions related to your child's emotional or mental health.

7. In the past 12 months (18 months for "Targeted sample"), 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**
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

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)..... 2
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 (18 months for "Targeted sample"), 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. 9a) 2
Refused ..... (GO TO Q. 9a) 7
Don't know ..... (GO TO Q. 9a) 8

8b. How helpful was the doctor or other health care provider in addressing your concern or answering your questions?

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

9a. During the past 12 months (18 months for "Targeted sample"), did your doctor or clinic refer your child for any Early Intervention services that the school district can provide? These services might also be 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 contact Early Intervention or Help Me Grow directly for you?

Yes ..... (GO TO Q. 9d) 1
No 2
Refused 7
Don't know 8

9c. 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

9d. 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

9e. Did you bring your child into Early Intervention/Help Me Grow for an assessment [AS NEEDED: Or did they come to your home for an assessment?]

Yes 1
No 2
Refused 7
Don't know 8

9f. Did your child qualify for any Early Intervention or Help Me Grow services? [AS NEEDED: Did the assessment show you're your child had a need for these services?]

Yes 1
No 2
Refused 7
Don't know 8

9g. 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, 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 services been for your child or family? Would you say…

Very helpful, ... (GO TO Q. 9j) 1
Somewhat helpful, or ..... (GO TO Q. 9j) 2
Not helpful? ..... (GO TO Q. 9j) 3
Refused ..... (GO TO Q. 9j) 7
Don't know ..... (GO TO Q. 9j) 8

9i. Is there anything keeping your child from getting these services or any reason you would prefer your child not to get these services?

_____

_____

9j. Did your child's doctor or other health providers follow-up with you after the clinic visit 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 (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 8

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

Yes 1
No 2
Refused 7
Don't know 8

11e. 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

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 reason you would prefer your child not to get these services?

_____

_____

11i. 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 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

13a. During the past 12 months (18 months for "Targeted sample"), 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:** _____
1. 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
2. IF YES TO 13b-1. THEN: What was that?	_____ _____ _____ _____	_____ _____ _____ _____	_____ _____ _____ _____
3. 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 after the visit 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. Have you noticed any examples of this type of coordination happening in the past year?

_____

_____

_____

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

_____

_____

_____

20. 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.

21. 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

22. What is your child's racial/ethnic background? 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
e. White/Caucasian	1	2	7	8
f. Other (Specify: _____)	1	2	7	8

23. 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

24. 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

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

Yes ..... (GO TO Q. 27) 1
No 2

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 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 5