ABCD Toolkit
Assuring Better Child Health Development through Connecting Clinics and Early Intervention/Early Childhood Special Education

Department of Health, with the Department of Education and Department of Human Services Maternal & Child Health Section P.O. Box 64882, St. Paul, MN 55164 Phone: 651-201-3760 http://www.health.state.mn.us February 2017
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Overview

Minnesota’s Assuring Better Child health Development (ABCD) Project is a quality improvement project designed to improve child outcomes through increased communication, care coordination, and collaboration between the child’s primary care clinic staff, early intervention/preschool special education providers, families, and other community partners.

A very basic work flow of this process looks like this:

A child ages birth-5 attends a well child visit and...

- Shows concerns on clinic developmental or social-emotional screen
  - or
- Has a parent with a concern about their development
  - or
- The provider identifies a concern.

Clinic staff make a referral for the child through the Help Me Grow Online System

Early Intervention/ Early Childhood Special Education staff receive the referral, complete tasks, and return feedback information to the clinic on the results of the referral.

The clinic receives the feedback, provider reviews and acts accordingly.

As teams engage in the ABCD project, they will discover the various ways in which the feedback loop may look different in their community, and use the quality improvement tools to test ways to overcome those barriers.
The ABCD project’s purpose is to improve the referral and communication feedback loop for developmental and socio/emotional health screening for children birth to 5 years between primary health providers and the early intervention/early childhood special education (EI/ECSE) system. A strong relationship between primary care and EI/ECSE system will:

1) Increase the number of children that are screened using a validated tool at the primary care level.

2) Increase the likelihood that children who have low or failing scores on screens are actively referred for appropriate early intervention/preschool special education services.

3) Maximize continuity and coordination of care for children by increasing the quality and quantity of communication between primary care clinics and families regarding early intervention/early childhood special education programs.

Primary care clinic staff, families, early intervention/early childhood special education providers, family members, local public health nurses, and other key community stakeholders will come together as a team to implement ABCD in their communities.

Several clinics and EI/ECSE staff have completed ABCD projects in Minnesota, the majority did so within a Learning Collaborative. While very, very helpful, the Learning Collaborative structure is not necessary in order to do an ABCD project.

This Toolkit includes tested protocols, standardized forms and trainings that a team could use to guide the work of their ABCD project and provides information on how to facilitate a Learning Collaborative (group of teams doing the ABCD project together).
Basic Timeline with Milestones

A basic ABCD project runs for 12 months, with an additional three months of preparation before launch. Here are the general activities, with milestones, for each quarter. These could be done with a collection of ABCD teams working together (Learning Collaborative) or just by one ABCD team. Events that would be done for the Learning Collaborative are marked.

<table>
<thead>
<tr>
<th>Time Frame</th>
<th>Milestones</th>
<th>Measurements of Completion / Deliverables</th>
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| At least three months before intended launch date, could take up to six months. | Form full project team:  
• Clinic project champion  
• Clinic data and administrative support people  
• Parent partners (2)  
• Key leaders from EI/ECSE  
Optional and Optimal:  
• Leaders from Children’s Mental Health providers  
• Local public health representative  
• Advocates for children/children with special needs | • Gain commitment from team members  
• Assure commitment to gather and share data as needed  
• Put in place mechanisms needed to provide financial and technical support for parent partners |

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<tr>
<th>Launch Session – 1st Meeting</th>
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| Launch! | • Identify team project aim  
Most likely a half-day meeting.  
If appropriate, include education on the EI/ECSE system, on screening tools, on referral best practices.  
| • Outline first steps in the improvement process and a path toward their ideal workflow for the referral and feedback  
• Determine data points to use for monthly reports  
• Establish times/dates for monthly meetings  
• Identify administrative contact and data contact |
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| **Monthly Meetings**          | • Ongoing- have Provider Champion run the meetings  
• Review data  
• Write PDSA cycles  
• Discuss tests and outcomes, plan improvements  
• Work on overall process flow chart  | Complete monthly meeting notes  
Compile monthly data |
| **Learning Collaborative**    | Teams have reported two months of data  
Project teams have implemented at least two PDSA cycles.  | During the session teams will:  
• Share their initial data  
• Share at least one completed PDSA cycle  
• Share about one barrier and possible ways to overcome it |
| Webinar 1: two months into the project: Teams will present their first PDSA cycles and outcomes, and the first experience with gathering data. | **Mid-Project Check In**  
(six months into project) | Work flow or other changes are completed or nearly completed.  
Run charts are used – data is compiled and team is reviewing charts at monthly meetings  | Team reviews completed work flow and identifies areas for improvement.  
Team creates plans to spread and sustain the improvement. |
| **Learning Collaborative**    | Spread/sustainability plans are in final phases.  
Team can articulate the value of the ABCD project and the relationships that were built | Team review final data run charts  
Team creates guidance for other organizations from lessons learned |
| Webinar 2: 9 months into project, Teams share plans for spread/sustainability | **Wrap-Up/Final Review**  
(within one month of end of project) | Project is completed.  
Team reviews and evaluates project efforts.  
Any final reporting is completed. |
Key Project Components

Quality Improvement

The ABCD project is designed to be a quality improvement (QI) project using the Model for Improvement from the Institute for Healthcare Improvement. Therefore, the project is time-limited, relies upon recent data, and uses Plan-Do-Study-Act (PDSA) cycles to complete the work. Because of this design, the project has been approved by multiple professional boards as a “portfolio activity” which means that pediatricians and family medicine doctors can use it as part of their licensing requirements.

The quality improvement aspects of the project make it more rigorous and potentially more effective than other efforts to change systems. Using the QI components in the ABCD project is highly recommended.

The ABCD project uses the Model for Improvement or Plan-Do-Study-Act (PDSA) as the central tool for accelerating improvement. As the team creates goals and measurements, they implement small changes, cycling through PDSA. It will be helpful to have all members of the team learn the Model for Improvement. The Model for Improvement was developed by Associates in Process Improvement and is promoted by the Institute for Healthcare Improvement (www.ihi.org).
Data

In the ABCD project, data is collected and reviewed monthly. There is no need to collect “baseline” data, just use the first month of collection as a quasi-baseline. If the project is done in a Learning Collaborative, then the data can be presented both as individual clinic data and in aggregate. In presenting and sharing the data, no identifiable data should be included. If the clinic or EI/ECSE organization has concerns about collecting and sharing data, data can be restricted to only the team members employed by that organization, but since the data is de-identified, that should not be a problem.

In past ABCD projects some clinics have gone through the Institutional Review Board (IRB) process (as did the Minnesota Department of Health) to see if they needed approval to use the data. None of the IRBs determined that the project needed review, as the data was both de-identified and only used for quality improvement.

A significant barrier to using the data for improvement is the difference between the data from the clinic and from the EI/ECSE organization. In most cases the clinic will refer children to a number of different EI/ECSEs, because they serve children from different school districts. Similarly, EI/ECSEs will serve children from a variety of clinics. The number of children referred from a clinic will not match the number of referrals received by their EI/ECSE partner. The data should be collected to help understand the overall process, but not expected to match.

The most common and helpful measures to collect: (Children = children ages birth to including 5 years)

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<tr>
<th>Measure</th>
<th>Numerator</th>
<th>Denominator</th>
<th>Notes</th>
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<tbody>
<tr>
<td>Percent (% of children completing a screen at their well child visit)</td>
<td># children completing a screen</td>
<td># children attending a well child visit</td>
<td>This includes both social-emotional screen and developmental delay screen. These could be separated if needed. Only count once, even if two screens were given. Do not count screens that took place outside of well child visit (from mailing or sick visit). For this measure, a denied screen (where parent chooses not to complete the screen) would be counted as a missed screen. If you want to measure denials, you’d need a different measure.</td>
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<tr>
<td>% of well child visits resulting in concern</td>
<td># children with a concerning score on a screen or other concern</td>
<td># of children with a well child visit</td>
<td>This measure would take into account a positive score on a tool, a concern from the provider, or a concern from the parent. This would not allow you to measure the number of positive screens, but it would be a good measure for recognizing concerns beyond the tool. In order to track this measure the clinic will have to manually review visit notes, since a “concern” from a parent probably won’t be noted in a searchable field.</td>
</tr>
<tr>
<td>% of screens with a concern score</td>
<td># of screens that have positive (concerning) score</td>
<td># screens completed</td>
<td>This measure is usually easy to find in the electronic record and is at least a minimum for how many referrals should be made.</td>
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<tr>
<td>Measure</td>
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<tr>
<td>% of concerns that resulted in referral</td>
<td># referrals to EI/ECSE (sometimes called Help Me Grow) from the clinic</td>
<td># well child visits resulting in a concern</td>
<td>The denominator for this measure could also be “# of screens with positive (concerning) score.”</td>
</tr>
<tr>
<td>% of referrals with feedback received</td>
<td># of referrals with feedback received by the clinic from EI/ECSE</td>
<td># referrals sent from clinic to EI/ECSE</td>
<td>This measure needs to have a timeline determined, which may need to be separated by child age. Birth – (including) 2 should have 45 days, 3-5 has 60 working days. If you want to combine these, use the 60 day timeline. Add 10 days for time for EI/ECSE to complete sending feedback to the clinic after the evaluation/assessment is completed. The simplest way of tracking this measure is to have the clinic keep a log of referrals sent and track when feedback is received on the log. If the clinic has referral tracking in place, that could be used, but some will have to create it.</td>
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Measures collected by the EI/ECSE partner

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<tbody>
<tr>
<td>Percent of referrals with feedback sent to referring clinic</td>
<td># of feedback forms sent back to referring clinic</td>
<td># of referrals received from clinic</td>
<td>This is a very basic measure which is used to ensure that the feedback forms sent to the clinic are received in the correct place. More detail which could be collected and would be helpful is: how many referred children were able to be contacted, agreed to evaluation/assessment, completed evaluation/assessment, were eligible for services, and began receiving services.</td>
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Measures for Early Childhood Screening

In some cases, ABCD teams have decided to include referring children to Early Childhood Screening into their process. Early Childhood Screening is a screening that is done by the local school district for all children prior to entering kindergarten (in the past it was referred to as Kindergarten Screening). All children need to complete one, regardless of if there is an existing concern. Most school districts do them for children ages 3 – kindergarten and in some districts the same staff who provide EI/ECSE also work with the Early Childhood Screening process. One of the complications of referring children for the screen is that there is limited access to the screen, depending on the school districts. Some districts, because of their size, only offer the screen two times a year. Also, as of December 2016, Minnesota did not have a statewide system for referring children to the screening.
Understanding the possible barriers, some teams do decide to work on the Early Childhood Screening referral also, using these measures:

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<tr>
<td>Percent (%) of three year olds referred for Early Childhood Screening</td>
<td># three year olds referred for Early Childhood Screening</td>
<td># of three year olds attending a well child visit</td>
<td>Children are eligible for this screen (done at the local school district) at age three. Some four and five year olds may have missed it, so a measure could be added to track the percent of those older children who did not already complete the screen who were referred.</td>
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**Plan-Do-Study-Act Cycles**

The Plan-Do-Study-Act (PDSA) cycles are most useful when used regularly and iteratively. A PDSA form (Appendix A) should be completed at each meeting, sometimes more than once.

Many team members are resistant to completing the PDSA forms because it feels like “busywork.” However, research shows that using the PDSA form to guide thoughtful testing of possible improvements leads to more sustainable change. The basic idea is that the team should not be deciding on a full-fledged process to implement, but should test pieces of the process, repeatedly, and implement portions as they prove worthy. This allows for slow and steady change, instead of a large rollout that doesn’t last.

Here are questions to ask in each section of the PDSA, these are also on the form.

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The PDSA Cycle for Learning and Improvement

- **Act**: What changes are to be made? Next cycle?
- **Plan**: Objective, Questions and predictions (why), Plan to carry out the cycle (who, what, where, when), Plan for data collection
- **Do**: Carry out the plan, Document problems and unexpected observations, Begin analysis of the data
- **Study**: Complete the analysis of the data, Compare data to predictions, Summarize what was learned

Jane Taylor, EdM, 2015
The iterative part of the PDSA process means teams may use several PDSA cycles to test different elements of a change, building up to implementing a strong change. For example, in looking at which staff person in the clinic should administer and score a screen, PDSAs could flow together:

**Improved and Documented Work Flows**

The information learned from the PDSA cycles, along with the expertise of the ABCD team and the data, together help the team improve their overall work flow, which they should update regularly, documenting at the end of the project. These will vary greatly depending on the team. For examples, see Appendix B.


**Multi-Sector Teams**

An ideal ABCD project team has active representatives from all of the different areas touched by the project. For most communities, this means:

- Parents and families – two representatives if possible
- Clinic staff
  - Medical provider champion – a doctor or nurse practitioner who is actively seeing children birth-5 for well child visits – *the value of having a provider champion cannot be understated - for change to be embedded in the clinic these leaders need to be involved*
  - Nurse or clinic administrator – someone who manages the referral process and understands how the referral is documented and tracked
  - Medical Assistant or other staff- someone who knows how the family receives and completes screens
- Local school district early intervention/preschool special education staff
  - Possibly the staff who follow up on referrals and do evaluations or assessments
    - If the evaluation/assessment staff are different from the referral tracking staff, this may be more than one person
  - If there is a regional collaborative partner managing some of the evaluation/assessment process, include them
- Local public health department – especially staff involved in screening young children
- Children’s mental health providers
- Early Head Start, Family Home Visiting, and other providers serving young children
- Other community stakeholders – potentially advocates for early childhood education or for children with special health needs

For a detailed overview of potential roles and responsibilities for the various team members, see Appendix C.
Family/Parent Involvement

Although potentially difficult, involving parents on the ABCD project team can help the team create more innovative and effective, family-centered improvements. Tips for recruiting and supporting parent partners:

- **Recruiting**
  - Aim for at least two parent partners (not one) – parents feel more comfortable when they are not the only one in the advisor role.
  - Create a clear list of the duties and expectations for the parent partners - Clearly detail the time commitment- which meetings are they expected to attend (should be all), how long will the meetings take, and how much preparation time is expected.
  - Ask clinic and EI/ECSE staff to help identify parents who might be willing to participate, this includes:
    - Parents of children who were in EI/ECSE when they were younger, or currently are.
    - Parents of children currently or recently patients of the champion providers.
    - Parents serving in local parent advocacy positions/organizations.

- **Ensure all team members understand and value the role of the parent partners**
  - Mark places on the agenda when parent comments are specifically asked for – parent partners may be left out of technical/clinic process conversations, so make a point to specifically ask for their input at key moments.
  - Spend time on the introductions at each meeting, making sure new attendees understand the value the parent partners bring to the team.

- **Equitably support the parent partners in their involvement**
  - In most teams, participants are reimbursed for their time as it is part of their jobs. For parent partners, if project team work isn’t part of their paid work, reimburse them for time, child care expenses, and mileage.
  - If the parent partner is open to it, arrange a time for a mini-orientation just for them, before the team meetings start. Go over what to expect, technical language that might come up, and stress the importance of them sharing their experience and insights.

One past parent partner said:

_I like being a part of an initiative, feeling involved in the community... I was surprised this type of thing didn’t already exist, that the organizations didn’t talk to each other. It was good to see everyone coming together for the betterment of the child. For the parent, the eye is only on the child, and I can’t imagine trying to connect or update all these organizations. The end goal is “I can focus on my child and know that all the paperwork, all the boxes that need to be checked, are in one spot... It’s a lot to keep track of.”_
Sustainability

The Model for Improvement, with the focus on incremental and tested change, is designed to have lasting impact when used correctly. For the ABCD project, sustainability means the process of embedding the changes into the processes strongly enough that the changes remain over time. A key tool for sustainability has been use of Health Information Technology (HIT) – the ways clinic systems (and school systems) can be altered to support the screening/referral processes and not rely on individuals to remember the changes. Here are a few examples of ways HIT has been used for this:

- **Smart Sets:** Some clinics and providers use a set of questions or prompts that are established for different types of visits. For example, for every three year old well child visit the prompts would remind the provider to look at vision, hearing, specific immunizations, etc. These sets of prompts can sometimes be altered for the entire clinic or by individual provider. Examples of prompts that could be added in these sets:
  - Complete developmental or social-emotional screen?
  - Discuss Early Childhood Screening with family?
  - Ask about developmental concerns?
  - Help Me Grow referral needed?

- **Referral Ques:** Connecting patients with referrals and follow up is an essential part of clinic care. Some clinics have developed ques that track the referrals and remind a care coordinator to follow up on them. This can be confusing when Help Me Grow is included, because of the time delay, but it can be very helpful.

- **Adding the Help Me Grow referral onto discharge steps for babies in the NICU.** Not all NICU babies will be eligible, but as many are a universal referral is a good idea. Putting the referral into the discharge steps prompts hospital staff to consider the possibility.

- **Tracking completed screens in same way that immunizations are tracked.** There are some health systems that have their records set up in a way that if a child comes in for a sick visit, a flag pops up notifying the provider if the child is behind on immunizations. If developmental or social-emotional screens are tracked the same way, then a flag could note this for a sick visit provider as well. Even if the screen could not be completed during the sick visit (which may be inappropriate), the family could receive one to take home and send back in a self-addressed stamped envelope.

Ways to promote sustainability that do not rely upon Health Information Technology include:

- Including Help Me Grow referral follow up on a specific clinic team member’s job description, so that if the person changes the responsibility remains.
- Reporting quarterly to the team or leadership on the % of required screens that have been completed and the % of positive scores that resulted in referrals.
- Including information on the referral process and Help Me Grow for new employees, especially in places where the providers rotate/change often – residents, etc.
- Establishing a consistent, system-wide screening schedule for the developmental and social-emotional tools.
Spread

Clinics and EI/ECSEs are working on the ABCD project because they see it as a valuable tool in improving care for children with suspected developmental or social-emotional delays. As the process proves helpful, the ABCD team should begin to think about their natural professional connections that will allow the project to spread. Many clinics are connected to larger health networks, so planning for this spread may be natural and should be considered at every step- if there are changes to the electronic health records that all clinics will use, how to educate peers about it, for example.

A complication of ABCD- the fact that clinics serve children in a number of different school districts and districts serve children who use a variety of clinics- is an advantage for spread. As the ABCD project makes strides with one clinic and one district, the team can then bring other clinics or districts into the project meetings and share learnings.

Spread should be considered in planning throughout the ABCD project, and should be a focus in the last quarter. Samples of spread activities:

- **Matching Meetings:** A team from one clinic met with another clinic and had members match up with their professional counterparts to discuss how the project worked in their position, i.e. care coordinator with care coordinator, nurse with nurse, pediatrician with pediatrician.
- **Peer to Peer Recruitment:** After the referral feedback process was established at one clinic, the champion pediatrician asked two doctors at clinics in the same system to test out the system and report back on data.
- **Regional Support:** As the early intervention outreach system is redesigned in Minnesota, team members are taking the project information to the regional collaboratives.

Learning Collaborative Approach

Minnesota ABCD projects have been done in a learning collaborative structure. This means that ABCD project teams come together at multiple points to collaborate on ideas and combine data for analysis. It would be possible to do an ABCD project without a learning collaborative, but the teams would miss out on possible benefits.

A learning collaborative needs to have a coordinator to facilitates events and manage the data. A leader from any of the ABCD project teams could do this, but note that it can take a lot of time, depending on the number of teams. Minnesota has completed a number of ABCD learning collaboratives, two were statewide, and two have included non-clinic partners – other community early childhood agencies which are also engaged in screening and referring (preschools, etc.)

It is very common for quality improvement projects in the health care setting to be done within a learning collaborative, but not necessary.
Lessons Learned from Past ABCD Projects

Barriers and Solutions

Clinic Screening Schedules
Many clinics have developed a clear and consistent protocol for screening for children birth -5. It is necessary for clinics to do this, in order to support healthy development for the children they serve. Research has proven that earlier intervention leads to better outcomes and that validated tools outperform “provider observation” in identifying concerns.

Clinics who are connected to larger health systems may use the ABCD project as an opportunity to standardize the screening practices across the system. In past ABCD projects, teams were sometimes surprised to discover the variety of schedules used within their system, and had to spend more time on setting the schedule than they originally planned for.

A county public health nurse may be available to advise a clinic on setting up their screening protocol and systems. At the state level, contact the MN Department of Health for support.

The use of standardized screening instruments to perform developmental and social-emotional screening in young children may pose challenges to some practices because of limited knowledge of reliable screening instruments and limited time during office visits to screen children. Parent report screening instruments eliminate these barriers by providing a quick and standardized way to screen children.

For an overview of standardized screening instruments and a complete list of recommended observational, parent report, and social-emotional screening instruments recommended for use please visit http://www.health.state.mn.us/divs/fh/mch/devscrn/.

Clinic and School District Changes
While the concept of care coordination is not new, many clinics are still in the process of establishing their internal processes for following up on referrals. This is especially true with referrals outside of the standard health networks, like referrals made through Help Me Grow. Within the health network, feedback is received on a timely basis, for every referral, not so within Help Me Grow. Referral coordinators develop processes to deal with these differences, but are often also developing whole referral coordinating processes at the same time, so it gets confusing.

Staff changes can impact the sustainability of screening, referrals, and follow-up. Staff in both types of organizations can change often, especially the front line staff who may be dealing most with administering the screens and following up on referrals. ABCD projects should work to make the process as uncomplicated as possible, and to develop ways to pass on that knowledge as staff changes.
The Help Me Grow system and the services provided for children with developmental and social-emotional concerns works differently in Minnesota. All states have some version, but Minnesota provides it for free regardless of income (not true in every state) and immigration status. In Minnesota the system is managed by the Department of Education, whereas many states house it within Human Services or Health or some combination of the three agencies. All of these differences mean that providers educated in or coming from other states — very normal for doctors — may have NO previous knowledge of Help Me Grow (HMG) or how it works, and may actually think they know how it works and be wrong. ABCD teams should find ways to embed an overview on the process into new staff training.

Clinic Resistance to Referring without Feedback
An ongoing issue for ABCD teams in improving the referrals and feedback loop is the barriers to sending feedback and the provider resistance to continuing to refer when they haven’t received feedback on previous referrals.

Both clinics and educators have a legal responsibility to keep information confidential. Clinics are responsible to get the consent they need on their end (HIPAA) and EI/ECSEs are responsible for their end. The main problem is that often the referral ends on a phone call or no-contact, at a place where the EI/ECSE has not had a chance to get a signed consent to share information.

One way that ABCD projects have addressed this problem is through having the clinic have the family sign a dual-directional consent form, allowing the clinic and EI/ECSE to communicate back and forth. The problem is getting that dual-direction consent form to the EI/ECSE. Also, some school districts may not accept the consent. Currently (December 2016), the online Help Me Grow referral system does not accept attachments. However, it may in the future. At this point, the options are to have the clinic fax the form to the EI/ECSE or to hold the form until it is requested by the EI/ECSE.

Consent is not needed for EI/ECSE to report back to the clinic that the family was not able to be contacted and to confirm that the contact information they have is correct. Consent is needed for EI/ECSE to give the clinic information such as evaluation results or whether or not the family agreed to be evaluated.

Past projects have created a standard Referral Feedback Form which can be found in Appendix E. The form is not necessary, but has been helpful for some communities.

**NOTE:** Early intervention/early childhood special education providers routinely request consent from families to get the medical records from the child’s clinic. This is a different consent, this is consent from the family to provide feedback to the clinic regarding the evaluation.
Factors that helped teams have a strong start to the project

- **Collaboration had already begun**: In some communities, representatives from the medical community and school district had already begun meeting together to strengthen coordination of care for children. These meetings included public health nurses, clinic leaders, children’s mental health professionals, parents, and other stakeholders. In some cases this was a formal gathering, sometimes a part of a separate initiative or project.

- **Medical community was embracing care coordination**: Both newly formed and long-standing clinics were placing emphasis on coordinating care and accessing community resources. The project is consistent with changes taking place through health reform.

- **Screening was in place**: The communities had already experienced a push toward implementing screening and had many venues in which screening was systematically taking place (clinics, public health, school districts).

- **Central intake was established**: In areas with multiple school districts (home of MN’s early intervention programs) a central intake process had been set up. In clinics, care coordination had begun and a staff person had been identified to lead the effort.

- **Powerful interagency support**: Leadership in the different agencies supported the project and staff time was dedicated to the effort.

- **Data was valued**: The push to use data to guide and evaluate the project helped gain buy in and support from leadership. For some communities, the database provided expanded clinic capacity and was used beyond the project.

- **Validated fledgling efforts**: Some district and clinic staff had already begun to build the referral and feedback loop, so the project was able to build on and expand their efforts.

- **State Online Referral System**: Minnesota’s Help Me Grow online referral system had been launched, a major step in streamlining the referral process.

Effective PDSA Cycles

These are small changes that the teams planned, did, studied, and then acted upon to help them reach the large goal of system change.

- **Establishing a consenting procedure**: For both the clinic and the early intervention evaluation or assessment team, it was very helpful to design an appropriate consent process and make it standard protocol. This meant asking every family for consent to share information between the clinic and the EI/ECSE team at the *beginning* of the process.
• **Increasing the referral expectations:** On the clinic side, encouraging practitioners to do referrals for all elevated screening scores, not just failed screens but also border line screens. Also, asking the referring clinicians to report to EI/ECSE what other referrals have been made (mental health, physical therapy, etc.).

• **Diagraming work flow:** Developing flow charts and diagramming the best way to complete the referral and feedback cycle.

• **Testing work flow:** Information sharing – sending records and seeing if they get into EMR – was it the right info, was it understandable or useful? What was the result of it? Identifying a referral to track and checking to see the results (will need to be done over time).

• **Tracking work flow and reviewing data:** Choosing a specific case to track, such as a child with a borderline ASQ score. Track the patient in the data base, report on if the feedback was received in a timely fashion.

• **Creating an expectation of communication:** Working with EI/ECSE staff at the district to create an expectation that they will, with consent, report back to clinics the outcome of all referrals. Using team created forms the team gained support from the leadership and trained staff on the procedure.

• **Adding stakeholders to the Team:** One team added a Head Start representative, bringing in their expertise and connection to resources.

• **Adding key questions to intake protocol:** One team added “have you had your early childhood screening done?” to the intake for pediatric patients. If the family answered no the clinic sent their name to the early childhood screening staff for follow up.

• **Acting on shared needs:** One team recognized a need for services for families with children 3-5 who had borderline ASQSE scores. They gathered resources and held an eight week parenting class and tracked the results. They saw a significant decrease in the ASQSE scores and used the information to apply for ongoing funding for the class.

**Innovative Improvements**

**NICU**

Babies in the NICU are often eligible for EI/ECSE services and should be referred through Help Me Grow. However, it is difficult for EI/ECSE to follow up on a referral made at birth, since the baby may be in the NICU during the time they would need to visit and do evaluation. One ABCD project worked with the hospital to embed a HMG referral within the NICU discharge process (a recommended process).

**Follow Along Program**

The Follow Along Program (FAP) is a free and voluntary program that provides periodic screening and monitoring of infants and toddlers at risk for health, social emotional or developmental
problems. It improves the identification of developmental and mental health issues at an early age, facilitates early intervention services for the child and links families and children to needed services. FAP is available in most MN counties and any child can be enrolled at their families’ request.

Some of the ABCD projects are concerned with children who received a referral to Help Me Grow but were not found eligible for services. Connecting those children with FAP is one way to continue to monitor the child.

Pre-Visit Screening

- **Phone Screening** - One ABCD team set up a pre-visit screen, where a Medical Assistant called families scheduled for a well child visit and offered to complete the screening tool over the phone. The completed tool was then put in the file for the visit, and a referral was made when needed.

- **Mail Screening** – One clinic system started mailing out the screens both prior to the well visits and for those children who were flagged as being behind on screens. After doing this for a little while they had about a 30% return on the screens.

Public Health Nurse Outreach

One clinic developed the practice of having a public health nurse (employed by the clinic) follow up with children who came in for a sick or urgent care visit and were behind on their well visits and screens. The nurse attempted to contact the families to schedule a well visit.

Other past ABCD team recommendations

For making a good referral (appropriate, with support for the family to follow through) from the clinic:

- **Giving the right screening tool**: Staff knows where the tool is and how to present it at check-in for the family.

- **Everyone doing the right tool**: Staff knows when to use which tool and are administering both developmental and socio-emotional/behavioral mental health screens, at appropriate ages 0-5.

- **Knowing how to do and interpret the tool**: Appropriate staffs are sufficiently trained to score and interpret the tools.

- **Physician makes the referral when appropriate**: Standards are set to ensure referral is made for borderline and failing screen scores, as well as when parent expresses concern.

- **Consent signed at the clinic to exchange information**: Family is informed of the clinics desire to share information with the EI/ECSE program and asked to sign a consent form for dual directional information sharing (allowing both the referral and the feedback report).

- **Active referral is made, and if possible, a copy of the consent form and screening results are included**: Clinic makes the referral, instead of giving the information to the parent and asking them to do it.
• **Annually having staff meet each other, build relationships:** Facilitate ways for coordinators at both the clinic and the EI/ECSE program to meet, face to face, to build understanding about their work and the overall referral/feedback loop.

For relaying the evaluation results back to the referring or associated clinic:

• **Consent signed at the beginning of the process:** District staff asks the family to sign a consent form to release the results of the evaluation to the child’s clinic, *whether or not the clinic was the source of the referral.*

• **Use one standard, user friendly form:** Use a simple, short form with enough information to be helpful but also short enough to be likely to be read. A sample form is included in the toolkit.

• **Include administration in process of creating the work flow:** Administration may want to weigh in on the appropriate form design and will be helpful in implementing a change in protocol for all EI/ECSE staff.

• **Assign responsibility for feedback:** Have a designated position on the EI/ECSE team who is responsible to send the feedback form and to make sure it gets to the right person at the clinic.

• **Build a relationship with key clinics:** Communicate directly with care coordinators at key clinics, meet at least annually to exchange information and keep updated when protocols happen. Also, educate clinic on EI/ECSE services and procedures.
For care coordination between clinic and EI/ECSE providers to be effective:

- **Feedback report is recorded in the Electronic Medical Record (EMR):** The clinic receives the report (most likely by fax) and scans into the EMR.
- **Care Coordinator notes feedback:** Report is viewed first by care coordinator who then enters outcomes on easily accessible place in the chart (a problem list for some) and flags it for the provider.
- **Provider reviews the outcome:** Notes it, makes additional referrals if needed, and checks on status at the next patient visit.
- **Include parents:** Make sure parents understand the care coordination service. Help them to see the benefit and make sure all appropriate consent forms are signed.
- **Designate responsible positions:** It is necessary to determine which position (care coordinator, nurse, etc.) at each agency (clinic, district office, and public health) is responsible for the referral and feedback loop. Identify this by position, not person, so that if turn over occurs the responsibility is not lost.
- **Keep good data:** The best way to keep ongoing buy in for the feedback loop is to keep data showing the outcomes – increased referrals, better tracking of children, etc. Check on the process periodically to keep it functioning and improving. Report on this to leadership.
- **Report on no-shows or refusals:** Determine the legally appropriate way of reporting back to the clinic when the referral results in a no-show or a refusal of services.
- **Timely communication:** Establish a time line for communication.
Appendix A: Plan-Do-Study-Act Form

❖ DATE:

❖ Objective for this PDSA Cycle:
  Is this cycle used to develop, test, or implement a change?

❖ What question(s) do we want to answer on this PDSA cycle?

❖ Plan:
  *Plan to answer questions: Who, What, When, Where*
  
  *Plan for collection of data: Who, What, When, Where*

❖ Do:
  *Carry out the change or test; Collect data and begin analysis.*

❖ Study:
  *Complete analysis of data;*
  
  *Compare the data to your predictions and summarize the learning*

❖ Act:
  *Are we ready to make a change? Plan for the next cycle*
Appendix B: Sample Final Workflows

These are sample flows from past ABCD projects, so may use different terminology.

Sample Internal Referral Feedback Workflow for Screening at Clinic

Clinics will vary in which staff will perform which of these functions. As part of the CCHD project, it will be important to identify these staff and engage them in the improvement process.
Early Intervention or Preschool Special Education Services Referral Report Workflow

Child visits clinic, completes a screening tool with a score that triggers a referral

Clinic sends referral directly to early intervention office at school district

District receives referral, assigns to staff for evaluation

Evaluators contact family and set up meeting

HMG determines appropriate district, sends them the referral

Family refuses evaluation or is unable to be contacted, referral is closed

Student comes in for evaluation, consent to send results back to clinic is requested

Federal refuses services, referral is closed

Student is determined to be eligible for services

Not available in all counties.

District sends this information back to the clinic

*Not available in all counties.

District Workflow
Referral Report Opportunity
Appendix C: Possible roles for specific team members


<table>
<thead>
<tr>
<th>Partner</th>
<th>Agency and Description</th>
<th>Roles and Responsibilities in ABCD</th>
</tr>
</thead>
</table>
| Clinic        | Primary Care Providers and Care Coordinators               | As a lead partner in the project, the clinic staff will be responsible to:  
- Administer a periodic developmental and socio/emotional health screening to all children ages 0-5.  
- Follow established clinic screening protocol and make appropriate referrals to early intervention/preschool special education services. NOTE: according to Federal regulations, parental consent is not necessary to make a referral to Help Me Grow.  
- Make sure the family is aware the referral is being made and discuss what the process will be (i.e. someone from the school district will contact them and talk about the next steps).  
- Refer the child either directly to the local early intervention/preschool special education program or through the state Help Me Grow referral system (online or by phone).  
- Receive and track referral feedback reports received from the early intervention/preschool special education providers.  
- When applicable, support the family to follow through on any recommended services from the service plan. |
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<tr>
<th>Partner</th>
<th>Agency and Description</th>
<th>Roles and Responsibilities in ABCD</th>
</tr>
</thead>
</table>
| Help Me Grow                                 | Help Me Grow (HMG) is Minnesota’s branding for the early Intervention system that includes child find, public awareness, and outreach. There are different levels for the system: state, regional, local, and all of these levels have different responsibilities within the system. More information in Appendix B. | If the primary care provider makes a referral through HMG, they will forward that referral to the correct local early intervention/preschool special education provider. The referral may include information for the EI/ECSE program if the primary care provider would like to receive referral feedback.  
Note: For ABCD purposes, it would be helpful if the Help Me Grow system notified the referring clinic as to which school district the child is being referred to, so the doctor can prepare the family. |
| Early Intervention/Early Childhood Special Education Program | The local school districts manage these programs which are responsible for providing infant and toddler intervention and early childhood special education services to all eligible children.  
More specific information about responsibilities is found in Appendix B. | These providers are responsible to receive the referral and if appropriate conduct the evaluation and the assessment of the child and family.  
Under Part C  
If the child is found eligible for services, then a team will be assembled a multi-disciplinary providers and family members, and the team will create a plan (IFSP).  
Under Part B  
If the child is found eligible at the evaluation, then a team is developed and that team creates a plan (IEP).  
The early intervention/preschool special education provider will secure parental consent, if possible, and return results from an evaluation and/or assessment to the primary care provider. |
<table>
<thead>
<tr>
<th>Partner</th>
<th>Agency and Description</th>
<th>Roles and Responsibilities in ABCD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Local Public Health</td>
<td>Part of the county services, local public health staff often lead complimentary programs like the Follow Along Program or Family Home Visiting that also support screening for children 0-5.</td>
<td>Often local public health works alongside school districts and clinics to provide screening for children. A public health nurse involved in ABCD could help to coordinate efforts, promote resources partners and families could use, and reach families who haven’t interacted with the district or a clinic with a screening protocol.</td>
</tr>
</tbody>
</table>
| Other Community Partners | Family or community organizations, other medical providers, mental health providers or organizations. | The roles and responsibilities of each community partner will vary, depending on the mission of each organization. Possible responsibilities may include:  
- Family support groups – educating families about the benefits of care coordination between the clinics and early intervention/preschool special education providers.  
- Mental health or other medical providers – coordinating care with the pediatric clinics and responding to needs outlined in early intervention plans. |
| Parents and Families     | Parent or family member with a child in the 0-5 age range, from the community.          | Provide insight as to the acceptability and feasibility of the project and activities for families who interact with the clinic, early intervention/preschool special education program, or both. |
Appendix D: Sample Run Charts

Number of Children Referred

Feedback Reports Received Late/Incomplete
Appendix E

Help Me Grow / Early Intervention / Early Childhood Special Education Referral Results Form

Please return by fax to the student’s primary clinic.

Student’s Name_________________________________________ Gender M F
DOB______________________

Referral Source ____________________________________________ Referral
Date______________

Service Coordinator/ IEP Case Manager________________________
School District_________________ Phone_________________

Outcome of the Referral

☐ Team was unable to contact parent
☐ Team contacted, but parent declined evaluation
☐ Team determined no evaluation was needed
☐ Team evaluated and student did NOT qualify
☐ Team evaluated and student did qualify

☐ Developmental Delay (DD)

Delays in following areas: Cognition Communication Fine Motor Gross Motor Social-Emotional Adaptive

☐ Speech/Language Impairment (SL)

Delays in following areas: Language Fluency Voice Articulation (these are education terms, not medical diagnoses)

☐ Autism Spectrum Disorder (ASD)
☐ Deaf/Hard of Hearing (DHH)
☐ Emotional/Behavioral Disorders (EBD)
☐ Other ________________________________
Service Locations

- Home Visits  Frequency ____________
- Inclusive Classroom  Frequency ____________
- Special Education Classroom  Frequency ____________

Team Includes:  EI/ECSE Teacher  OT  PT  SLP  DHH  Vision

Other Referrals Made (ie Dev. Disabilities, CPS, ECFE, PH Nursing, HeadStart)

___________________________________________

Student’s Primary Clinic________________________________ Date
Faxed________________________
Clinic Fax Number______________________________
Glossary

Key Terminology

_Early Intervention/Early Childhood Special Education – EI/ECSE_

For the purposes of this Toolkit, we will be using the term “early intervention/early childhood special education” to refer to these programs that together serve children from birth – five years old. This includes:

1. Infant/toddler early intervention services for children birth to three, under Part C, and
2. Preschool Special Education services for children three to kindergarten, under Part B619.

Part C and Part B619 are parts of the federal Individuals with Disabilities Education Act (IDEA), the legislation that mandates these programs.

_Clinic Staff_

The term “clinic staff” refers to doctors, nurses, care coordinators, administrators, and others who work at the child’s primary care facility (most likely a clinic).

_Evaluation -- Under Part C (0-3 years)_

• Procedures used by qualified personnel to determine a child’s initial and continuing eligibility under this part consistent with the definition of infant or toddler with a disability.
• Initial evaluation refers to the child’s evaluation to determine his or her initial eligibility under this part.

_Assessment-- Under Part C (0-3 years)_

• Ongoing procedures used by qualified personnel to identify the child’s unique strengths and needs and the early intervention services appropriate to meet those needs throughout the period of the child’s eligibility and includes the assessment of the child…and the family-directed assessment of the child’s family.
• Initial assessment refers to the assessment of the child and the family-directed assessment conducted prior to the first IFSP meeting.

_Evaluation and Assessment-- Under Part B619_

The definition for evaluation is very similar to the definition under Part C, however, assessment in Part B619 refers to an ongoing process as opposed to a specific part of the evaluation process.

_Service Plan_

The plan created by early intervention/preschool special education team to provide appropriate services to student. The Individualized Family Service Plan (IFSP) is used for children 0-3 and the Individualized Education Program (IEP) is for children over 3.
## Acronyms

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Meaning</th>
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<tbody>
<tr>
<td>AAP</td>
<td>American Academy of Pediatrics</td>
</tr>
<tr>
<td>AAFP</td>
<td>American Academy of Family Physicians</td>
</tr>
<tr>
<td>ABCD III</td>
<td>Assuring Better Child Health and Development</td>
</tr>
<tr>
<td>ABCD</td>
<td>Communities Coordinating for Healthy Development</td>
</tr>
<tr>
<td>DHS</td>
<td>Department of Health</td>
</tr>
<tr>
<td>EIS</td>
<td>Early Intervention Services</td>
</tr>
<tr>
<td>FERPA</td>
<td>Family Educational Rights and Privacy Act of 1974</td>
</tr>
<tr>
<td>HCH</td>
<td>Health Care Homes</td>
</tr>
<tr>
<td>HIPAA</td>
<td>Health Insurance Portability and Accountability Act of 1996</td>
</tr>
<tr>
<td>HMG</td>
<td>Help Me Grow</td>
</tr>
<tr>
<td>IDEA, Part C</td>
<td>Individuals with Disabilities Education Act (IDEA, Public Law 108-446), Part C, refers to federally mandated delivery of services for special needs children from birth through 2 years old</td>
</tr>
<tr>
<td>IEIC</td>
<td>Interagency Early Intervention Committees – Minnesota’s 12 regional entities responsible for child find (finding children eligible for the services), public awareness, and outreach.</td>
</tr>
<tr>
<td>IEP</td>
<td>Individualized Education Program</td>
</tr>
<tr>
<td>IFSP</td>
<td>Individualized Family Service Plan</td>
</tr>
<tr>
<td>MDE</td>
<td>Minnesota Department of Education</td>
</tr>
<tr>
<td>MDH</td>
<td>Minnesota Department of Health</td>
</tr>
</tbody>
</table>
References

Information from the following resources was used to create this toolkit:

- Institute for Health Care Improvement
- Pilot Sites: Anoka County, Ramsey County, Olmsted County, and St. Louis County
- “Coordinating Care between Early Intervention and the Primary Care Medical Home” a project of the Illinois Chapter of the American Academy of Pediatrics, Advocate Health Care’s Healthy Steps for Young Children Program, and The Illinois Bureau of Early Intervention
- National Academy for State Health Policy and The Commonwealth Fund
- Centers for Disease Control: National Center on Birth Defects and Developmental Disabilities
- MN Department of Education: Kara Tempel
- MN Department of Health: Susan Castellano, Shawn Holmes, Katy Schalla-Lesiak, Tessa Wetjen
- MN Department of Human Services: Glenace Edwall, Catherine Wright