Developmental Screening Stakeholders Meeting
Monday, December 12, 2016
Discussion Summary and Action Steps

Executive Summary

Project Overview

In December 2016, 53 stakeholders gathered to explore the potential for collective action to create positive change within developmental screening processes and system(s) in the state of Illinois. The stated meeting purpose was to:

- Develop and agree to a shared understanding or vision of the purposes and importance of developmental screening
- Understand who is doing what and where gaps may be
- Outline feasible steps each party can take to improve systems and processes

The meeting discussion was organized to generate shared goals with an accompanying road map of the most relevant and feasible action steps to pursue in the next 12-18 months. Facilitators worked to surface tangible opportunities and/or strategies that could be compelling enough to attract funding *and* fill or fix identified system gaps.

Project Planning and Structure

A smaller planning team led development of the agenda and structure for the convening. Participants on this team represented the Governor's Office of Early Childhood Development, Illinois Department of Public Health, Ounce of Prevention Fund, EverThrive Illinois, Sargent Shriver National Center on Poverty Law, and the Legal Council for Health Justice.

Together, this group built an overview of the current state of developmental screening systems which was shared at the meeting. They also identified four domains across which positive changes are needed:

1. Data: We want to be able to collect and use child level data
2. Systems: We want to ensure our child-serving systems are prepared to systematically process results of screening and support the referral process
3. Parent Support: We know parents need to better understand the importance of developmental screening, why it is done, and how to access it for their children
4. Workforce: We need better workforce supports to ensure implementation of developmental screening is done appropriately, is understood as important, is accessed by parents, and that discussion of results and referrals are appropriately addressed

Stakeholders each participated in two brainstorming sessions, selecting from these topics. A complete inventory of each discussion is included in the appendix, but the most promising menu of actions from which to choose a strategic direction are outlined, by area, below.

Stakeholder Vision for Developmental Screening Data

We want to be able to collect and use child level data to evaluate how we are doing in screening, referring children to services, and conducting follow-up. We would like this data to be longitudinal so we can also see the effects of Early Intervention services on later academic achievement. Finally, we would like to see improvements in how information is collected and analyzed to eliminate duplication and ensure a complete data set.

Priorities proposed by the small planning group are:

1. Advocate for and monitor progress on unduplicated child level screening data as part of the Illinois Longitudinal Data System (ILDS), incorporating lessons learned from communities including Oak Park-River Forest
2. Continue to improve the ability to report Child Find data at the aggregated community level
3. Explore the possibility of using I-CARE as a centralized, shared data system for recording screenings and follow-up
4. Explore the possibility of making Child Find reporting mandatory

The full menu of items identified by the larger meeting's participants includes:

Data	Menu of Action Steps
Data Tracking	Assign a unique identifier to each child to increase our ability to maintain unduplicated counts (Dept. of Innovation and Technology exploring currently)
	Desired indicators: # screened, screening results, # referred, # assessed, # received services
	Maintain a database of 'gray zone kids' (those who do not qualify for a referral, but may be at risk in future, or may need to be prioritized for early childhood services)
	Improve access to community level/ rural data to form a complete data set
	Track screenings in a system like, or similar to, I-CARE or EMR; systems group also suggests DCFS Statewide Provider Database and GP3S System developed by Project LAUNCH
	Develop a tracking app to circumvent paper form challenges
Data Mapping	Map the data owners, access points, processes and procedures, and barriers (ELC conducted a system scan that can be shared)
	Create a visual demonstrating how many systems potentially screen a child and the reimbursement per child within each system (GOECD offered to develop and use)
	Plot private insurance against public insurance screening data to demonstrate the gap between the two (IECAM is also mapping aggregated screening services)
Data Messaging	Build the case for the state RE cost savings through early screening (without enabling funding cuts due to duplicated counts) – consider cost savings analysis
	Position screening as an expansion of immunization work (ex. house tracking data on same card)
	Use Oak Park –River Forest Collaborative as a model to scale out coordinated data approaches
Data Opportunities in Near Future	
	Intersect with these efforts and/or systems: • Illinois Longitudinal Data System (ILDS) Project • Department of Innovation and Technology • State's Enterprise Data Warehouse/ISBE partnership

	• Upcoming cross sector trainings between HV, Child Welfare, ECE, Homelessness service providers

Stakeholder Vision for Developmental Screening Systems

We want to ensure child-serving systems can systematically and consistently process the results of screening and support referrals. Ultimately, we want to be sure children are connected to the right services at the right time. Specific areas of improvement include:

- screening protocol (more standardization)
- reimbursements for developmental screening services by early care and education providers
- cross-agency coordination through the referral process so children get needed services
- reduction in the number of families referred who cannot be contacted
- follow-up supports for families via referrals and sharing of results
- improved feedback loops between providers and systems

Priorities proposed by the small planning group are:

1. Universally integrate, across systems, state-endorsed referral forms and procedures; create more feedback loops and garner permission from parents for sharing across systems
2. Simplify and streamline the HFS care coordination toolkit for medical providers easy reference
3. Explore the possibility of legislation or HFS administrative action to require that all EMR (electronic medical records) vendors in Illinois incorporate a validated developmental screening tool in the EMR as well as develop capacity for electronic referrals
4. Building on training materials and resources already developed by communities, increase capacity for developmental screening in licensed child care settings
5. Explore the role of community health workers in monitoring screening results and conducting follow-up – closing feedback loops and referring children to the right services

The full menu of items identified by the larger meeting's participants includes:

Systems	Menu of Action Steps
Medical Providers	Better engage the Academy of Family Medicine (Illinois Chapter of the Academy of Pediatrics already supportive) and work with both entities to positively communicate the importance of screening to entire medical team. Training can include: • standardized messaging around who, why, what, and how screenings should be performed • how to discuss developmental screening results with parents • what Early Intervention is and how the referral process should take place • what referrals to LEAs for ECSE are and how they should occur • establish a clear protocol for children ages 3-5 or those not eligible for EI • the right supporting documents when they make referrals; how to follow through on the referral • inclusion of all members of the child's medical team (e.g. nurses and medical assistants
	Advocate for reimbursement to providers for extra time to communicate about and perform screenings & referrals
	Explore methods for medical clinics to provide screening questions electronically with information integrated into EMRs; excerpt care coordination tool in HFS toolkit (facilitates communication between child care provider and pediatrician) and simplify it to make more universal
Screening Tools	Engage EMR Vendors and MCOs to ensure valid and reliable tools are used
	Consider accessibility to validated screening tools (ASQ is expensive, Easter Seals limited)

Referral Process	Standardize ECSE referral form: • include additional contacts for the family to reduce instances in which families can't be reached • help doctors find the appropriate school district for sending forms • improve feedback loop by standardizing referral form parent and medical provider can sign to request an evaluation Revise the EI Referral and Fax back Forms to: • Make more universal for different providers making referrals to EI • include parent permission for direct communication on first page, not the second • be less medically focused and more broad for use by all
	Fully explore use of standardized referral forms (must be written into procedures by state agencies), electronic referrals (including encryption or joint cooperative agreements)
	Consider a help line for parents and providers seeking referral (ex. E. St. Louis)
	Explore partnership between EI, Child Care, and Home Visiting systems to create a more seamless referral process
Early Care & Ed.	Find reimbursement opportunities for early childhood providers to receive payment for developmental screenings; address child care providers' concerns about losing children from program who are found eligible for services.
	Convene a group of providers (CFCs, child care and home visiting programs) to explore feasibility of becoming a Medicaid-eligible provider for developmental screening reimbursement: 1. Could ISBE use ECBG as a state match to draw down Medicaid funds? 2. What do providers need to administer a validated tool? What type of training should be provided? 3. Understand # of screenings and children involved. 4. Pros and cons of opening provider eligibility in this manner.
	Establish a standard protocol that includes the following information: which screening tools you use, how often you do the screening, how do you report it, what kind of training, who administers the training; brainstorm performance measures around developmental screening for providers and programs
	Work with DCFS on new licensing for child care providers; work with CCAP/DCFS to reach non-licensed and licensed child care providers who don't participate in Excelerate
	Target child care providers using the ASQ family portal/ assign an administrator at the child care who has a direct relationship with the family; train programs and administrators on how to interpret results and explain them to parents
	Advocate for all providers to require reporting data through ISBE Child Find project or another reporting system
Misc.	Advocate for process point 'owners' so each player is clear on their responsibilities at each stage of the process
Systems Opportunities in Near Future	
	Closely follow the EI DS Pilot planned by CFC 5 to provide trainings for the CFC and community partners

Stakeholder Vision for Parent Support

We want to ensure parents understand the importance of developmental screening. We hope to do this by making them part of the process, helping them feel supported, improving communications throughout the screening and referral steps, and educating the broader community about why it is important that children are screened. Ultimately, because parents are the first teachers for their children, we want them to lead the screening process and continually be an active part of the conversation. We also want the process to become normalized – to do this, we need to reduce stigma and fear and insist on a strength-based approach.

Priorities proposed by the small planning group are:

1. With meaningful parent input, develop clear, asset-based messages to parents about the importance of developmental screening.
2. With meaningful parent input, develop appropriate mechanisms for dissemination of these messages.

Parents	Menu of Action Steps
Parent Support	Better support parents to fill out the Ages and Stages Questionnaire (from systems group)
Parent Education	Create a public health campaign on developmental screening, based on existing resources (see What I Can Do Campaign, CDC Milestones, Breast Cancer Awareness)
	Establish consistent language in talking to parents about the importance of screening (use peer to peer approach, require as topic in Head Start family meetings etc., work through child care centers to reach parents)
Systems Improvements	Identify champions (family practice doctors and in communities)
	Advocate for a one stop shop for resources online and through parent networks in communities
	Promote coordination in communities via shared intake, etc.
Parent Engagement Opportunities in Near Future	
	Child Find funds – could they be targeted for use on this? Look at Georgia, California, Rhode Island for ideas/ case studies

Stakeholder Vision for the Workforce

We want better workforce supports to ensure developmental screening is conducted consistently and appropriately, including:

- Efficacy in screening and referral
- Effectiveness in familial communication strategies and content
- Inclusion of physicians, nurse practitioners, physician assistants, infant mental health consultants, home visitors, classroom teachers, and social workers
- Mutual understanding of who is doing screenings, and who *can* screen
- Reimbursement

Priorities proposed by the small planning group are:

1. Train workforce, across systems, on state-endorsed referral forms and procedures
2. Train workforce, across systems, on asset-based messaging with parents
3. Develop funding for a central helpline/clearinghouse for providers?

Workforce	Menu of Action Steps
Workforce Competencies	Establish a set of mutually agreed upon competencies: • education and training • necessary supports • required knowledge of systems • understanding of the screening tool • ties to family engagement • bi-directional 'buy in' • protocol in instances of a positive screen • feedback loop • referrals to interventions beyond EI
Workforce Training	Train the workforce: • asset-based messaging around Developmental Screening • communication with parents • cross system collaboration that highlights the value in each system • understanding the screening tools
Misc.	Build messaging to change thinking around a 'hard' referral
	Offer a helpline for providers
Workforce Opportunities in Near Future	
	Highlight and share resources that can support providers like communication guides and resources prepared by the Collaboration for Early Childhood (Oak Park) and AAP Trainings

Appendix – Raw Data

Data Breakout Groups

What is the overarching goal for this area? What positive change do we want to see as a result of our work?

Telephone Group:
- Ability to collect longitudinal data at the child level, for example to see the effects of EI services on later academic achievement (i.e. data on EI return on investment)

In Person Session #1:
- We want to know if children have been screened and have unduplicated counts.
- It would be ideal to have a unique identifier for each child. It was shared that Department of Innovation and Technology is looking to create such identifier. In addition, within Innovation Zone child care centers are looking to collect information on number of children receiving services.
- Beyond the screening data, we need to be able have numbers that show full process: #Screened→ #Referred→ #Assessed→ # Received services.
- We should also be thinking about data on children who have private insurance.
- Also need to consider the “gray zone kids” (children who, by a narrow margin, did not qualify for a referral after screening but may be at risk for referral in future without some type of referral to a support service/program).
- Need access to community-level data that is publicly available for children receiving Special Ed services. Currently, rural data gets suppressed because it is so small.
- In addition, it would be ideal to know what the different workforce needs are (according to what children qualify for). This will help know and understand what the capacity of the system to serve children is and what it should be. It can inform resource allocation at state and local level.

In Person Session #2:
- Group #2 echoed what Group #1 shared. They also made following points:
- We want to see Child level data. In addition to knowing who received screenings also need to know the results.
- Data should also show # of times a child was screened.
- We need to understand and have data showing the groups within screening systems (e.g. Doctors).
- Benefits of work would be: Improve systems, catch gaps, reduce duplications, and ability to target services to children who need them especially considering limitations on resources.

What are 3-5 ambitious but feasible strategies that will *make the most difference* in the identified area?

Telephone Group:
- Improved messaging to parents/families to reduce stigma and fears of “labeling,” to encourage them to consent to data sharing.

In Person Session #1:
- Having a Unique Identifier for each child in order to reduce duplication.
- Show cost savings to the state that exists in screening and serving children early on, which prevents intensive interventions from being necessary later in life.

- Get Data issue prioritized in the larger systems efforts so that different systems/agencies match their data.
- Create inventory/ mapping of the following: Who has the data? How do we get it in order to have better assessment of who's doing screenings and who kids are? What's the process and procedure? What are the obstacles? (It was shared that a systems scan was created within ELC which shows what is available and where data lives. It will be shared out).
- Have a unified data system for screening

Additional notes:

- Jon Furr is going to pass much of ILDS responsibility to Charlie Rosemond at OECD.
- Anticipate barriers in moving data from system to system. We should take current work of ILDS and the barriers they encountered as lessons for obtaining data sharing agreements.

In Person Session #2:

- Track screenings in a system like I-CARE which already does this for immunizations. When inputting results, need to be careful with identifiable data so perhaps another options is to just check if screening was completed or not.
- Ensure messaging and awareness to parents/families is part of the work.
- Have screenings be an expansion of immunizations so doctors will pay attention to it and can check it off. It was shared that Rock Island created an immunization card that has developmental screenings information on back.
- In response to paper forms being lugged back and forth and at times being lost perhaps we can have an App created.
- Have performance measures around developmental screenings for those providers/programs required to complete them.
- Elevate screening data prioritization within Early Intervention.
- Look at Electronic Medical Records (EMR) and I-CARE systems and assess if screening data screens or fields can be added.

Additional notes:

- Not all health providers are reporting screening data. For example, there is an FQHC that collects information on screening data in EMR system but is not required to pull report and share out with anyone.
- It was noted that residency zip code is needed if we want to plot screening data against IECAM population data.

Are there tangible opportunities you see that can be seized in the near term? In the long term? Do you see any potential funding sources for work in this area?

- The state's Enterprise Data Warehouse includes a new partnership with ISBE.
- The ICARE data system (which includes childhood immunization data) is widely available to a broad range of providers. IDPH confirmed that developmental screening data can be added to ICARE, but it's not clear how much time or resources would be needed.
- The scheduled cross-sector trainings (between HV, child welfare, ECE, homelessness service providers) would be an excellent opportunity to get information and messaging out to providers.
- The current work of the Illinois Longitudinal Data System project (ILDS).
- Department of Innovation and Technology (DoIT), which is looking to create a unique identifier.

- Learn from Oak Park-River Forest Collaborative

Is there information we need to take into consideration or something we need to know as we move forward in this area?

- Is ICARE widely utilized by enough private providers to make this a helpful data system strategy?
- Privacy concerns
- Transitions in leadership
- We don’t have baseline data available at local level
- We need to make information unidentifiable
- Oak Park is as an example of a community that has done much work around developmental screenings data. Their data includes: # children need monitoring, # referred, # assessed, and findings of assessment.
- Need to understand that even within each screening system we may not have effective feedback loops and ability to complete follow-up.
- There may be a need for staff development so that systems/agencies are more adequately prepared to work appropriately across its own system.
- State is duplicating costs by having a child screened by more than one system. We need to be strategic about the narrative we share with State so that they do not misinterpret duplication as reason to cut funds. We need more funds to be able to screen more children. We also need funds to be able to work towards obtaining an unduplicated count of children being screened.
- It was suggested that perhaps a visual that shows how many systems can potentially screen a child and the reimbursement per child within each system should be created. OECD Executive Director, Cynthia Tate, said she’d be willing to speak on issue and communicate using such visual.
- We should look to obtain and plot private insurance versus public insurance screening data. Plotting one against the other will help make case for gap.
- Need to put together and communicate cost-savings analysis of early intervention.

Systems Breakout Groups

What is the overarching goal for this area? What positive change do we want to see as a result of our work?

Telephone Group:

1. Improved consistency of referrals for EI and other developmental services to get children to the right service at the right time.
2. Reduced number of families referred who cannot be contacted (due to transient housing and contact information)
3. Improved funding for developmental screening services (this makes the assumption that some providers don't screen appropriately because they don't get reimbursed for this service).

In Person Session #1:
We want to ensure our child-serving systems are prepared to systematically screen, systematically process results of screening and support the referral process. Some considerations:

4. Strategic or standardized protocol in screening
5. Cross-agency coordination to ensure children get the services they need
6. Follow-up supports for families via referrals, sharing screening results
7. Feedback loop and referrals to other systems (such as home visiting)— was added day of meeting

As a group, we decided to break up discussion between the world of medical providers and the world of early care and education. The first topic discussed was in the frame the medical provider world. The group wanted the overarching goal for providers to be all 3 considerations: strategic or standardized protocol in screening, cross agency coordination to ensure children get the services they need, and follow-up supports for families via referrals and sharing screening results.

- Strategic or standardized protocol in screening: there could be more stakeholders involved with messaging to parents how screenings help their child.
  - Academy of Pediatrics is extremely supportive of developmental screenings, there was concern that the Academy of Family Medicine not engaged and should be. These entities can positively communicate the importance of screenings for doctors.
    - In high need communities, they don't have pediatric doctors but there are always medical providers. Is it realistic or feasible?
  - Anyone who is part of the medical team (nurses, medical providers, nurse practitioners, Medical Assistants) should be a part of these efforts and involved in meeting the overarching goals.

Some of the CHALLENGES with the current status of developmental screenings for medical providers:

  - Doctors don't know sometimes where or how to refer children who are older than 3 to early care or education programs. Early Intervention is more simple because it is a uniform system with one (providers just have to find the CFC), but other early care and education centers have different forms depending on where you live and what program it is. Doctors found it easier just to refer to Early Intervention even when the child is not qualified (because they are too old). It was stated that individuals in this group have seen many referrals of children who are too old for Early Intervention.

- Parents are given the ASQ with little guidance. Depending on literacy skills and support, there is not much assistance given to parents to complete this questionnaire.
- Medical providers also tend to give little or no information to the parents about the results, and if they do give information, they do not give the parents the results in a way that can be used for skill building and greater parent-child interaction.
- Providers need to be comfortable discussing the results of the screening as well. Part of the reason for this is the time challenge at a well-child visit; many doctors do not have the chance to go through questions with the families.
- Providers are also untrained in discussing developmental screening results with parents.
- Some pediatricians ask only a few questions rather than a full, comprehensive ASQ screening—this is usually because the tool is not in the EMR
- The EMR also often dictates what is asked by pediatricians, which in many cases tends not to be a full screening and providers cannot be reimbursed unless a full screening is completed for 96110 billing
- Many providers do not understand what Early Intervention is-- they do not know that it is a developmental program, not a medical model.
- Some providers are choosing not to refer to Early Intervention, even though the law says 5 days. Instead it is more of a “wait and see” tactic.
- Referring to other early childhood programs does not happen. All referrals tend to go to Early Intervention. One reason may be because it is harder to refer to other programs because they do not all have a standardized form for other programs (like ECSE or home visiting or child care). They also may believe that Early Intervention can refer these children into different programs, so they tend to flood Early Intervention with referrals that EI cannot assist with. It is also more time consuming to refer to different programs when Early Intervention has one form that is easy to complete.
- Once the referral happens, there is no follow through. There is not a point person that the CFCs can talk to at the doctor’s office that can work with the CFC to get the child the services they need, and providers often do not see fax back forms
- Providers when making referrals don’t include supporting docs.

In Person Session #2:
In this group, we decided to discuss primarily these systems in the world of early care and education. What are the challenges through the perspective of early care and education that individuals face?

- Child licensing requirements. There is nothing within basic licensing that requires or financially supports developmental screening. QRIS has challenges too in terms of follow-up and supports to be able to make modifications to program or add staff to better serve children needing IEPS/IFSPs.
- There is not a system in place or funding on the child care level that supports a workforce that does these screenings. There are no programs to educate and assist child care providers.
- The quality of developmental screening is also a concern for this group. There needs to be some sort of baseline with standardized protocol because there is currently none at the moment.

        - Standard protocol has to answer these questions in order to have this baseline: which screening tools you use, how often you do the screening, how do you report it, what kind of training, who administers the training
        - We need better outreach. CPS and their child find program is a model for outreach at the LEA level; it is available in lots of settings, lots of different days, almost anyone can access it. They are going into the community and bringing together partnerships between LEAs and the family, which tends not to happen in other parts of the state.
            - However, what does CPS do if they are not eligible for these systems? There tends to be a lack of follow up/tracking/referral for kids who are not eligible for EI or SPED.
    - There is a burden on the parents to know all this information about these systems. There is more responsibility on the parent to know what developmental screenings are and ask for them—they need education and tools.
    - There is no shared message that all stakeholders hold for these systems. Many parents have negative connotations associated with screenings, where those who are screened mean that there is something wrong with them. Instead, stakeholders & providers need to push the message that screenings are an opportunity for parents to learn more about their children and invest in their growth and development.
        - We need to know our system better as stakeholders as well; we have to educate others, so educating ourselves have to be a top priority in our concerns.
        - We need to transition to a strength-based system that celebrates child and family success.

What are the challenges we have seen in terms of cross-agency coordination?

    - In Aurora, they now have a shared intake process and they implement community wide screening. There has been success in this shared intake process where if they refer a family and they do not get the referral for EI, the door is open for families for other levels of support.
    - One way to coordinate between agencies is to create a database for resources to know what systems are open and accepting referrals. Currently, there is no such database that tells let us know whether or not referrals were successful; many of these families fall through the cracks and get no services because of overcrowding or closed locations of assistance.

What are 3-5 ambitious but feasible strategies that will *make the most difference* in the identified area?

Telephone Group:

5. Consistent training and messaging for all providers who are performing developmental screening (who, why, what, how). Share the message that screenings should be conducted with parent engagement and in appropriate settings.
6. Improve referral forms to include additional alternate contact people for the family (grandparents, mom's best friend, child's godparent, etc.) in case the family's phone number or housing changes.

7. Explore the use of electronic referral systems (such as the DCFS Statewide Provider Database and the GP3S system developed by Project LAUNCH) to reduce barriers to referral and enrollment. The Illinois Department of Innovation and Technology (DoIT) could be engaged in this effort.
8. Convene a group of providers (such as CFCs, child care providers, home visiting programs) to explore feasibility/ desirability of becoming a Medicaid-eligible provider for developmental screening. Discussion items include:
    a. Could ISBE use ECBG as a state match to draw down Medicaid funds?
    b. What do providers need to do in order to administer a validated tool?
    c. Understanding # of screenings and children involved.
    d. Pros and cons of opening provider eligibility in this manner.
9. Broadly publicize and encourage the use of the standardized referral forms (which give HFS the ability to analyze the data).

In Person Session #1:
Strategies and opportunities that this system could do that have been successful and that can be feasible and tangible:

- Medical providers can involve peer to peer approaches in their systems, or they could have a parent who is willing to chat with other parents about their experiences with and developmental screenings, EI and ECSE. This would mean practice would identify someone to be an ambassador to the programs—either staff person or a parent.
    - Example, COFI works with parent leaders and have used a peer to peer approach. Most recently in the last quarter, through the South Side Learning Network, COF has peer advocates in their program. It was stated that through these advocates, hearing a family's approach and using the peer to peer approach helped engage parents with the screening.

- A help line for providers could make the referral process more successful. This would help a provider who had questions about the process or is stuck with a referral, and the person on the other line can walk them through the process.

    - Example: In East St. Louis, they have a resource and referral line that can make the connection to any referral line (LEAs, CC RNRs, EIs)
    - Many parents are not ready to be referred, so parents use this line as well as a resource.
    - At St. Anthony Hospital there is a developmental support project where there is a person who the provider sees for concerns or questions about a patient. They can be the connector that works with providers and they even go to EI appointments with the families as the point person between the provider and the family. Unsure how feasible it is at this point because of funding.

- A standardized ECSE referral form could help accelerate the referral process and make it easier on providers.
    - There are many patients that are not in their doctor's LEA, doctors need to know how to get to appropriate school district and who to send form to as well.
    - Not all providers have a directory of the LEAs in other areas of Illinois.
    - Getting the information back to the providers that the evaluation was completed

has been weak as well. The feedback loop is not strong for ECSE referrals. There are not fax back forms as in EI nor is there even a standardized referral form that parent and medical provider can sign to request an evaluation.

With little time left we moved on to the Early Care and Education providers focus.
Strategies and opportunities that we can roll out statewide:

- Child cares are the group that is most difficult to reach in terms of ensuring that dev. screenings take place. Using the ASQ family access portal could make screenings more accessible to families and providers without the extra time spent in the doctor's office or child cares trying to administer.
    - ASQ has a family portal that is accessible 24/7 but not everyone is using it.
    - It is good for programs, families, and children. It meets Excerate standards as well.
    - As a parent, they would click on a web link, fill out the screening, screening results go to the administrator of the screening (ex. Referral specialist in CCRNRs)
        - There are 16 resource and referrals and each one has a family specialist. They periodically check the family access portal to see what screenings come in and what follow up needed for the families that have completed it. It could be a referral to EI, SPED, or other early care and education program.
        - This is very similar to Easter Seals.
    - At the Collaboration for Early Childhood at Oak Park, there is an individual at the provider level that asks as an administrator that accepts the screening into the system, reviews the results, and gives resources to the families about the results of the screenings. Most people felt that it would be better to have the administrator be someone at the child care since they have a direct relationship with the family
        - There has to be training for programs and administrators on how to interpret results and how to explain screening results to parents.
        - There is a cost component

Possible strategies and opportunities for cross systems coordination:

- Those children who aren't eligible for Early Intervention can be directed to a different program (such as home visiting, or quality early care program or maybe they need both); how can that be done?
    - There could be a partnership between Early Intervention and the Child Care system – Child Care Resource and Referrals can give families a range of options for programs that they can sign their child up, so there needs to be this communication in place for those who do not qualify for EI. It is crucial to hold onto that child and give them the services they need.
    - Develop a letter that if the child care provider makes a referral to EI or Early Childhood Special Ed, the letter can show that the child was checked on a certain day and a referral was made, so then they can send that to the pediatrician. That way the doctor is in the loop, and that the doctor can follow up with the family if need be.
        - There is a care coordination tool in the HFS toolkit that allows communication

    back and forth between the child care provider and the pediatrician (but it needs to be made more universal).

- Early Intervention is the perfect no wrong door system – EI with sufficient funding could serve as that link across child and family serving systems by making referrals and connections to appropriate programs for the child and family beyond EI.
  - Example: In Kane County (CFC 4), there is a single point entry for home visitation programs (central intake).There is a generic referral to determine what kind of program the child may qualify for, and specialists will talk with the family to see if they need head start, home visitation, or other resources.
  - McHenry County has a EI and Childcare partnership initiative.
- Some states (such as Rhode Island) have their screening results online, where parents can give permission to share results with medical or child care providers.
  - There was discussion around adding these results to ICARE. The schools and medical providers would have access, but schools would only have read-only access (which shouldn't be a problem).

In Person Session #2:

- Changing the way we see child care could heavily impact the ways screenings are done. Working alongside DCFS in creating new licensing for child care providers can be the first step in impacting what "best quality child care" means in terms of developmental screenings.
  - It was also brought up that working with CCAP/DCFS for non-licensed child care providers who don't participate in EXCELERATE on developmental screenings could reach more providers and create more widespread messaging about this important screening.
  - Many programs are waiting to be mandated to include developmental screenings in their required tasks they must do. Currently, there is no mandate until you reach Silver in Excelerate, so there needs to be more support to do the work.
  - There needs to be similar requirements and shared expectations throughout early care and education for doing the screening and recording screenings, as well as support from the outside for these screenings to be done.
- There is no mandate to make providers report how many screenings they do a month, so EI officials get uneven reports of months of no referral or an overflow of data. If everyone was required to report data through ISBE Child Find project instead of it being optional, EI could have better data in which months show more screenings to send to ISBE.
  - Reporting data could help stakeholders find out how many individuals are not eligible for EI and what happens to them, it could help discuss why EI is so important to the public, and it could show the needs that our children have. We have to make the data <u>actionable</u>.
  - We do not have the zip code of the family when they are referred, so data is not accurately reflecting situations in different counties, b/c it reflects where screening took place only. We do not know how many children we are actually reaching because data collection issues.
- There also needs to be clearer responsibilities marked out for all stakeholders involved

with screenings; there is not clear instructions on who is in charge of what part of the process.

- There is a very real barrier of parents that don't screen their child because they don't know what the screening is and only thinking of screening for possible concern. Other barriers include that some families do not have the opportunity to screen because of their location.
    - In Englewood & Greater Grand Crossing community, parents are not educated in what screenings are, so there is a movement to educate families about this opportunity. Sometimes, children are screened in the doctor's office but parents do not even know that was done because there is no conversation between providers and parents about these screenings.
    - Getting families to the screening sites can be difficult. It can take multiple appointments for families to attend one appointment, and then when they do come, they have no idea what they are doing there.
- Child care may not be fully ready for implementing a referral process. They tend to have this fear of referring out (mostly fear of referring to ECSE) and pushing the child out of their program, because losing kids from their program means a financial loss.
    - Child care providers need to be better educated in the difference between assessment and screening. Assessment is not screening.
    - It is still unknown how screenings can be embedded into the child care program. Maybe taking a look at Excelerate can help create a connection between developmental screenings and the requirements of a child care program. Providers need to see it as a parent-engagement tool!
    - Providers also worry that it will offend parents to ask for a screening because of the false messaging of screenings diagnosing problems rather than celebrating milestones.

Challenges of feedback loops?

- Feedback loops do not exist currently.
- EI Fax Back Forms have to be faxed from the provider to EI, so there have been some problems with that. Forms are two pages, so many providers tend to only scan one page or forget to tell the parent to fill out both pages. This is a problem because the second page gives permission for EI and families to communicate directly.
    - One suggestion was to make entire form one page so providers and families wouldn't forget to fill out the full form.—and miss filling out release of info section
    - Another suggestion was to make the forms less medically descriptive and more broad so could easily be used by other programs.
    - Having a universal, state branded formal request form for providers/parents can fill out to ask the school for Special Education evaluation should be readily available to doctors and early care programs.
- There are no guidelines or instructions for medical providers and others about this process of referrals.
    - When someone leaves from an agency or medical practice who has truly understood the system in place, there is no one to pick up where they left off in

most cases.

Are there tangible opportunities you see that can be seized in the near term? In the long term? Do you see any potential funding sources for work in this area?

1. An EI Pilot is being planned by CFC 5 to provide trainings for the CFC and community partners. The pilot concept has been approved by the feds, and DHS will submit policies and procedures to the feds for approval. There is potential to expand the learnings from this project, once implemented.
2. HFS has been collaborating with DCFS around HEDIS measures. It is possible to pull out data for DCFS children because they have

Is there information we need to take into consideration or something we need to know as we move forward in this area?

Telephone Group:

1. The EI standardized referral form was intended to be electronic, but there were more barriers than expected (including data security) that could not be overcome with the budget restraints at the time. It was a strong proof of concept but we should be careful to define the elements clearly.
2. Regarding the use of standardized referral forms, this would need to be written into procedures by state agencies (such as DCFS) to ensure statewide use.
3. Regarding electronic referrals, DCFS would need encryption or a joint cooperative agreement.
4. HFS reported that MCOs are very interested in developmental screening, but they have difficulty assuring that when they pay for a screen, that a valid and reliable tool was used. Some providers are using home-grown screens developed by their EMR vendors. We would need to engage EMR vendors in this discussion as well.
5. DCFS experiences a challenge in having school districts accept special education referrals. Challenge in standardized referrals and when the school district will accept them. Sometimes they say no more screenings. Also, taking any standardized form and writing it into DCFS procedures.
6. Some internal work at DCFS needs to occur, for improved communication, data sharing, and follow-up between DCFS and the Erikson project.

In Person Sessions:

What information do we need to know moving forward in order for the medical providers to be better engaged in these systems?

- Individuals in early care and education would like to know how to contact medical providers because providers are very difficult to reach.
- They would like to know how to make screenings a priority for med providers as well as part of Standard Operation Practice.
- In East St. Louis, individuals are noticing the lack of well-baby checks in a doctor's office because of barriers to accessing healthcare providers (such as transportation, lack of doctors, cost of a visit). Equity is a huge part of why children are not being screened, especially in rural communities.
- We have no idea what is happening for employee sponsored or marketplace insurance doctor visits; there is no data that stakeholders can see to determine how many referrals are made. Would like to have that data.
- There was discussion around adding a requirement for providers to have onboarding and follow-

up training on dev. screening and making referrals.

  - Have this embedded into the medical records system – instead of one or two questions, have the whole ASQ pop up.
    - This is challenging b/c EMRS are really set up for adult care systems and the vendors don’t work together.

Parent Support Breakout Groups

What is the overarching goal for this area? What positive change do we want to see as a result of our work?

1. Parents will be informed of their role.
    a. Parents as their children's first teacher.
    b. Parents will engage with their children
    c. Parents will be seen as the leader of the screening process and of the tool. They should be actively part of the conversation.
    d. Parents will advocate for their children to be screened and their involvement in the process.
2. Parents will understand developmental screening.
    a. Families will understand how this can help their family
    b. Developmental screening as part of their role as parents in learning about their child's development.
3. Parents will access developmental screening
4. There will be universal language in communicating messages about developmental screening.
    a. Strengths-based
    b. Normalize developmental screening, use as a guide for typical development
    c. Reduce stigma and fear
    d. Consider using other terms (e.g.: learning check-up, "Look at what your child can do")

What are 3-5 ambitious but feasible strategies that will *make the most difference* in the identified area?

1. Create a public health campaign on developmental screening, based on existing resources
    a. Look at What I Can Do Campaign; CDC Milestones
    b. Examples: Breast Cancer Awareness encouraging monthly breast check-up; Governor proclamations
2. Identify champions
    a. Family practice doctors
    Not all children are seen by pediatricians, as some of them go to family physicians. There are some family physicians who are skeptical about the value of developmental screening. It is important to look for family practitioners who can help champion developmental screening.
    b. In communities: have conversations at ground level on developmental screening among stakeholders
3. One-stop shop for resources
    a. Online: When parents search for developmental screening on Google, what do they see?
    b. Network of parents (in communities) that they can approach when they have questions or concerns on developmental screening as not everyone has access to internet resources
4. Parent education: It is important to have consistent language in talking to parents about developmental screening. The following opportunities for parent education were suggested.
    a. Start prenatally
    b. Peer-to-peer approach
    A parent leader from COFI shared how she and other parent leaders go door-knocking to talk to parents about developmental screening and talk about their personal experiences about the process, and stress that developmental issues may be correctable

    c. Doctors and staff trained to explain screening benefits and engage parents in the process.
    d. Include as required annual topic in Head Start family meetings and other regular parent meetings at preschools, child care centers

Are there tangible opportunities you see that can be seized in the near term? In the long term? Do you see any potential funding sources for work in this area?

1. Work with current resources
    a. Existing services (eg: child care →although not all child care centers are involved in direct screening, they can be part of the process by educating parents to ask their doctors for screening)
    b. Promote coordination in communities (eg: shared intake)
2. Work within current routines, reimburse for additional time (eg: doctor’s check-up)
3. E-learning for professional development for child care providers
4. Use Child Find funds

Is there information we need to take into consideration or something we need to know as we move forward in this area?

Importance of centralized/shared database

Miscellaneous additional thoughts
1. Look at what other states are doing (e.g. Georgia, California, Rhode Island)
2. Tap Brooks Publishing as a resource for data management
3. Look into high need communities that lack health care resources for screenings and services following referrals
4. Need to establish trust:
    a. In the system
    b. That parents know their children best

Workforce Breakout Groups

What is the overarching goal for this area? What positive change do we want to see as a result of our work?

In Person Session #1:
The group agreed with the guiding principle that we need better workforce supports to ensure that the implementation of developmental screening (DS) is done appropriately. The “workforce” in this context includes infant mental health consultants, home visitors, classroom teachers, physicians, and social workers. There is a misunderstanding about *who is doing* screenings and *who can* do it. The group agreed that there needs to be messaging that screenings are occurring in diverse settings and a lot of individuals are doing screenings. While DS is occurring in multiple disciplines, there is also duplication and we are asking parents to do a lot. Is there a way to share data?
The group discussed the competencies around developmental screening, including education/training, supports, and knowledge of systems. There needs to be an understanding of the screening tool and what that means. Developmental screening ties into family engagement, including how to learn about that particular family and how do to have what can be a difficult conversation with the family about screening results and next steps.
The health care (HC) providers that were part of this first group identified some keys issues from their perspective:

- Timing and availability of fitting in a DS and adequate discussion given their time constraints;
- HC providers have other occasions (independent of when a DS is being discussed) to talk about milestones with parents and should use those opportunities;
- HC providers may refer-out but often do not hear back; and
- In terms of Medicaid reimbursement, there is no incentive for providers to bill for the ASQ in FQHC.

The accessibility of the validated screening tools was identified as an issue. For example, not everyone has access to validated tools and it was noted that the ASQ is an expensive tool. Easter Seals offers a free and confidential on-line screening tool that parents can use to help guide and keep track of their child’s growth and development during their first five years of life. While this is a helpful resource, it may limit quality and the level of parent engagement as results are sent directly to parents and may not offer an opportunity for the workforce to engage with the parents as they would if providers are doing the screening.

In Person Session #2:
The group agreed with the guiding principle that we need better workforce supports to ensure that the implementation of developmental screening (DS) is done appropriately. The “workforce” in this context includes a variety of professionals. It was recognized that parents are also doing DS. Parent participation is important and the parent engagement piece can get overlooked by professionals doing DS.

The group identified the core competencies that we would want the workforce to have:

- Bi-directional “buy-in”;
- Engaging in feedback loops;
- Engaging parents;
- Making referrals to interventions (other than EI which is a common referral) and knowing what other interventions to offer as a referral; and

- Knowing what to do when a positive screen occurs.

The following challenges or barriers were identified:

- Time and capacity (e.g., what can I do within 15 minutes of time with families?);
- Changing people's thinking around "hard" referrals;
- Access to validated screening tools because the ASQ is expensive;
- Access to referrals (a standardized fax back form may be one helpful strategy); and
- Complications that develop when a child turns 3 years old and the services offered by school districts vary.

What are 3-5 ambitious but feasible strategies that will *make the most difference* in the identified area?

In Person Session #2:
The group identified the following strategies:

- Provide for across-the-board *messaging* about DS that is not deficit-based;
- Offer various *training opportunities* focused on
  - *Communication* to (i) help the workforce feel comfortable talking to parents, and (ii) give parents the language to use when advocating for their child if they think there is a concern,
  - *Cross-system collaboration* centered around understanding and seeing the value in each system, and
  - *Understanding* the screening tool*;*
- Make validated screening tools more widely available, such as making them free and universal (other states provide for the ASQ to be free and online);
- Provide for an effective "*feedback loop*" and an *accessible data sharing* system –
  - Incorporate DS electronically into an I-pad, have parents complete an ASQ on the I-pad while waiting in the doctor's office, and have the results uploaded to EMR; and
  - Enable cross-system data sharing, such as one that models itself after the Illinois Comprehensive Automated Immunization Registry Exchange (I-CARE), which is a web based immunization record-sharing application developed by IDPH that allows public and private healthcare providers to share the immunization records of Illinois residents with other physicians statewide; and
- Elevate the work of certain communities, such as the Collaboration for Early Childhood (Oak Park), and identify such work as a best practice.

In Person Session #2:

The group identified the following strategies:

- Forms need to be branded statewide (e.g., use of standardized fax back form for referrals);
- The state acquires a license for the ASQ online (with family access) and offers it for free to the workforce;
- Highlight and share resources that can support providers, such as communication guides and resources prepared by the Collaboration for Early Childhood (Oak Park) and AAP trainings; and

- Offer a helpline for providers.