Coordinating Medical Homes and Community Services:

A Resource for Enhancing Referrals and Care Coordination among Primary Care Medical Homes, Early Intervention Service Providers and Community Service Providers

A guide to implementing screening, referral and follow-up for children at risk for developmental delay

Release Date: November 2015
Dear Early Childhood Service Provider:

Enclosed you will find a resource we hope will be of great use and value to you. This toolkit is designed to help you initiate a referral to Early Intervention services for children with suspected developmental delay, and to receive information back from Early Intervention about the outcome of the referral. This provider toolkit has been developed by Illinois Healthy Beginnings II (IHB2). IHB2 was a three-year project with funding from The Commonwealth Fund to the Illinois Department of Healthcare and Family Services (HFS). The project was administered by the National Academy for State Health Policy (NASHP). Collaborators on the project were the Illinois Department of Human Services (DHS); Illinois Chapter, American Academy of Pediatrics (ICAAP) and HFS. The goal of the IHB2 Project is two-fold:

- To ensure that Illinois children with suspected developmental delay or risk factors receive coordinated comprehensive care in which providers interacting with the family are aware of each other, appropriately access a variety of services, and collaborate to ensure the best possible outcomes are achieved for the child; and
- To create support for children and their families who may be at risk for developmental delay or disability but who do not meet Early Intervention or special education (SPED) eligibility guidelines.

To encourage success in meeting these goals, the purpose of this toolkit is to provide a referral resource for enhancing care coordination among primary care medical homes, early intervention service providers, and community service providers that work with Illinois children and their families. To this end, we have included similar information for care coordination to include home visiting (especially as related to the care coordination work of both the Maternal, Infant and Early Childhood Home Visiting (MIECHV) program and the American Academy of Pediatrics (AAP) Building Bridges Among Health & Early Childhood Systems project related to daycare and child care). This recognizes that linking medical homes to home visitors, childcare providers, and providers serving homeless children and families, enables the PCP to:

- Provide more comprehensive care and
- Increase knowledge of access to resources not typically available in a medical home.

Likewise, by collaborating with the medical home, the home visitor, childcare provider, and providers serving homeless children and families may be able to:

- Communicate the family’s health needs and risk factors back to the PCP,
- Increase opportunities for referral to additional services or consultation,
- Reinforce the need to use referrals for additional services, and
• Reinforce the need to use the medical home (not the emergency room) for primary health care.

We know that children and families can benefit from access to a broad range of developmentally appropriate and family supportive community-based services. As such, it is critical that there be an effective and sustainable process to ensure families are appropriately referred and can access such needed resources. We hope this toolkit, by showcasing key components of follow-up and referral models as they apply to the Early Intervention referral process and fundamental aspects of care coordination protocols among medical homes, home visitors, and/or child care providers, will provide a starting point for you to help build or enhance your other referral and follow-up efforts and care coordination protocols.

Sincerely,

The Illinois Chapter, American Academy of Pediatrics,

The Illinois Department of Healthcare and Family Services and

The Illinois Department of Human Services
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ACKNOWLEDGEMENT OF FUND SUPPORT

We would like to acknowledge the following organizations for their financial and resource support:

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

- The National Academy for State Health Policy (NASHP), an independent academy of state health policymakers dedicated to helping states achieve excellence in health policy and practice.

- The Illinois Department of Healthcare and Family Services (HFS), responsible for providing healthcare coverage for adults and children who qualify for Medicaid and for providing child support services to help ensure that Illinois children receive financial support from both parents.

- The Illinois Department of Human Services (DHS) charged with providing Illinois residents with streamlined access to integrated services, especially those who are striving to move from welfare to work and economic independence, and others who face multiple challenges to self-sufficiency. DHS has responsibility for the work of Early Intervention, home visiting services and child care providers.
Children and families benefit from access to a broad range of developmentally appropriate and family supportive community-based services including home visiting, childcare and homeless services. It is prudent to develop an effective and sustainable process to ensure families are appropriately referred and can access a wide range of needed resources. The content of this toolkit showcases key components of follow-up and referral models as they apply to the Early Intervention referral process. It can serve as an example to aid in building or enhancing additional referral and follow-up endeavors among medical homes, home visitor, childcare providers, and providers serving homeless children and families.

**Toolkit structure and module content**

This toolkit has been divided into four care coordination practice sections for all users: screening, referral, follow-up, and documentation. This framework includes key components and integral features addressed and/or considered in developing operational referral and follow-up techniques for an effective care coordination model.

Included in this guide are: a glossary of terms, frequently asked questions, forms for an effective care coordination protocol, and helpful provider resources for referrals and education.

**Module content**

This guide includes a wide range of resources and tools that have been developed to support each interpersonal practice section. While the information about care coordination is standardized, the toolkit information can also be accessed by interprofessional need: childcare provider, home visitor, homeless service provider, or medical home. This access design allows you to focus on the specific information you might require.
INTRODUCTION

Illinois has systems in place to ensure that young children are offered comprehensive developmental screening and other services through a range of systems and providers as well as a range of prevention and intervention programs available to young children under the age of five. However, barriers in care coordination hinder Illinois child health and community service providers from meeting the goal of ensuring that the developmental needs of all young children and their families are met from the very beginning and continue to be met throughout the early childhood period.

In Illinois, the DHS Early Intervention program estimates that approximately 43% of children referred to a local Child and Family Connection (CFC) for assessment may be at high risk, but are not eligible for Early Intervention services. Of that 43%, approximately 13% are not successfully contacted by the CFC because of incomplete or inaccurate information given during the referral process. There is an additional group of children who do not participate in an assessment because the parents/guardians perceive that the child is not at risk for developmental delay.

Children and families benefit from access to a broad range of developmentally appropriate and family supportive community-based services including home visiting, childcare, and homeless services. It is prudent to develop an effective and sustainable process to ensure families are appropriately referred and can access a wide range of needed resources. The content of this toolkit showcases key components of follow-up and referral models as they apply to the Early Intervention referral process and also provide a starting point to aid in building or enhancing additional referral and follow-up endeavors among medical homes, home visitor, childcare providers, and providers serving homeless children and families.

While this toolkit was written with attention to developmental concerns and from the perspective of the medical home, the best practices, tools, and protocols are applicable and adaptable for any service provider wanting to develop an effective care coordination protocol for children and families in need of a wider variety of services.

Background of Illinois Healthy Beginnings II

The Illinois Healthy Beginnings II (IHB2) project was launched in 2010 to identify the best sustainable practices for assuring better child health and development. IHB2 strove to provide effective referrals and care coordination across screening, treatment and prevention programs, ensuring that all children (including those at risk) are linked to the services that best fit their needs. The project was funded by a grant from The Commonwealth Fund to HFS as part of the Assuring Better Child Health and
Development (ABCD) III initiative. The project was administered by NASHP. Partners in the initiative were ICAAP, DHS and HFS.

Given the project focus, ICAAP, DHS and HFS (among others) are in a unique position to support these children and their families. Through Illinois Healthy Beginnings II (IHB2), participants were offered helpful and effective care coordination and access to local resources that serve these children. The introduction of standardized referral forms, referral fax back forms, and Individualized Family Support Plan (IFSP) summary reports, enhanced the quality of care coordination and positively impacted the experiences of participants.

Illinois Healthy Beginnings II (IHB2): Coordinating Medical Homes and Community Services was a project of Assuring Better Child Health and Development III (ABCDIII), in partnership with NASHP, HFS, DHS, and ICAAP, bringing together medical homes and Early Intervention and Community Service Providers (CSP) in order to improve communication and collaboration on behalf of children with or at risk for developmental delays. The goals of the project were to:

- Ensure that Illinois children with suspected developmental delay or risk factors receive coordinated comprehensive care in which providers interacting with the family are aware of each other, appropriately access a variety of services, and collaborate to ensure the best possible outcomes are achieved for the child; and
- Create support for children and their families who may be at risk for developmental delay or disability but who do not meet Early Intervention or special education (SPED) eligibility guidelines

This toolkit initially focused on care coordination between Early Intervention and medical homes. However, the focus has expanded, due to the fact that initiatives for MIECHV home visitors and childcare providers adopted these protocols and use versions of the care coordination forms.

**Background of Maternal, Infant and Early Childhood (MIECHV) Program**

Because of the statewide and national concern for children and families enrolled in Medicaid with access to a primary care provider, but using the hospital emergency room for primary care, ICAAP has collaborated with DHS to increase use of medical homes. We are able to work together in part because of funding through the Maternal, Infant and Early Childhood Home Visiting (MIECHV) program. Authorized by the Patient Protection and Affordable Care Act (ACA) that was signed on March 23, 2010, the MIECHV Program was established through a federal grant process issued jointly by Health Resources and Services Administration (HRSA), and the Administration for Children and Families (ACF). The purpose of the program is to respond to the diverse needs of children and families and provide an opportunity for collaboration and partnership at the federal, state, and community levels to improve health and
developmental outcomes for at risk children through evidence based home visiting programs.

MIECHV is designed to use evidence based home visitation as a strategy to:
  - Strengthen and improve the programs and activities carried out under the Title V Maternal and Child Health Services Block Grant Program
  - Improve coordination of services for at risk communities
  - Identify and provide comprehensive services to improve outcomes for families who reside in at risk communities

Targeted participant outcomes include:
  - Improved maternal and child health
  - Prevention of child injuries, child maltreatment, and reduction of emergency department visits
  - Improvement in school readiness and achievement
  - Reduction in crime or domestic violence
  - Improvements in family economic self-sufficiency
  - Improvements in the coordination and referrals for other community resources and supports

The evidence based Home Visiting program models used in Illinois are:

- **Early Head Start, Home Based** (EHS)
  Serving low-income pregnant women and families with children birth to age 3.

- **Healthy Families America** (HFA)
  Serving at risk families with children from birth to age 5.

- **Nurse-Family Partnerships** (NFP)
  Serving first time low-income mothers from pregnancy until the baby turns two years old.

- **Parents as Teachers** (PAT)
  Serving families with children from birth to age 5.
Background of ICAAP Child Care Projects Addressing Care Coordination

Childcare providers (both center-based and home-based) often spend significant amounts of time with young children and have extensive opportunities to observe their behavior, patterns of social engagement (or the lack thereof), and routines such as feeding, sleeping etc. In addition, health and safety issues in out-of-home childcare settings can range from simple to complex. Early education and childcare professionals routinely handle certain health matters, such as responding to a minor injury or developing materials and procedures based on individual State Licensing and Regulation Information. However, when faced with more complex health concerns, such as a child’s potential developmental delay or “at risk” factors, care coordination in the form of information sharing with the child’s/family’s medical home could greatly benefit the child and her/his family.

ICAAP believes that:

- A connection with a childcare provider gives the physician a view into the family’s home life and can be critical to his or her ability to provide care.
- The childcare provider can share important information with the family to reinforce health care.
- The childcare provider can make or support referrals to Early Intervention when there is a developmental concern. Using a standardized referral form, the childcare provider can identify:
  - Information about the child
  - Why the referral was made
  - The referring party (in this case the childcare provider)
  - To whom the referral was made (which CFC).

Target Audience

The utilization of an established care coordination protocol enables children and families to receive coordinated, comprehensive care. This means that providers interacting with the family are aware of each other, can appropriately access a variety of services and be capable of collaborating to ensure the best possible outcomes are achieved for the child.

This toolkit is designed to assist providers (i.e., child care, Early Intervention service providers, education providers, home visitors, primary care providers, those serving homeless children and families, and others) who serve families with young children (birth-5) in providing effective and sustainable practices for referral and follow-up processes to ensure that these children are linked to appropriate services that best fit their developmental needs, specifically:
• Families with children who are eligible for Early Intervention or SPED because they have been determined to have developmental delay or risk factors; and
• Families with young children who are considered "at risk" for developmental or behavioral problems, but are found not eligible for Early Intervention or SPED.

The tools provided will enable families and children eligible for Early Intervention or SPED to connect with developmentally appropriate and family supportive community based resources. We know the importance of intervening early and providing an appropriate referral for these at risk children and families who are NOT eligible for Early Intervention or SPED. This is paramount to reducing the need for potential/future longer term treatment. All stakeholders are challenged to ensure that these families and young children are not only appropriately referred to existing community resources, but also that they are actually able to access the resources.

In addition, the toolkit provides care coordination procedures and protocol examples to enable the same audience to share important information with medical homes and participate in the development of an anticipatory/proactive plan for appropriate services for the child and family, integrating the recommendations of multiple professionals and service systems; thus,

• Assisting the family in accessing needed services and resources,
• Facilitating communication among multiple professionals,
• Avoiding duplication of services and unnecessary costs,
• Optimizing the physical and emotional health and well-being of the child, and
• Improving the child's and family's quality of life.
Structure of Toolkit

This toolkit has been divided into four care coordination practice sections for all users: screening, referral, follow-up, and documentation. Discussion will include the topics of:

### Screening

- Use of both surveillance and screening by pediatric health professionals in determining whether a child requires further evaluation
- What to consider when establishing an office protocol for addressing developmental concerns, including the Who, What, and Why of all involved in the screening process
- The benefits of using a validated screening tool to identify delays
- Guidance for discussing the results of the screening with the families in an appropriate and sensitive manner

### Referral

- Establishing a process for making a referral
- Using a standardized referral form to ensure accurate transfer of information

*NOTE: The Standardized Illinois Early Intervention Referral Form included in Appendix C of this toolkit enables you to expedite effective information exchange, because needed parent/guardian consent that meets both Health Insurance Portability and Accountability Act (HIPAA) and Family Educational Rights and Privacy Act (FERPA) requirements is also built into this form.*

- Being aware of resources in the community that can provide services to the family, and when to use them, including Prevention programs, Early Intervention and Special Education.
- Staff responsibility for overseeing the referral resource guide and maintaining accurate information
**Follow-up**

- The importance of a medical home establishing a follow-up procedure to ensure the family made contact with the referral agency and were able to access services
- Repeatedly following-up with the family will ensure they are matched with the most appropriate resource for their needs

**Documentation**

- How documenting will assist the organization in determining the success of their referral process, and how to improve referrals in the future
- What needs to be documented to enhance care coordination
- What tools need to be in place to enhance care coordination

This framework includes key components and integral features addressed and/or considered in developing operational referral and follow-up techniques for an effective care coordination model.

This guide includes a wide range of resources and tools that have been developed to support each practice section. Included in this guide are: a glossary of terms, frequently asked questions, forms for an effective care coordination protocol, and helpful provider resources for referrals and education.
The Value of Care Coordination

The American Academy of Pediatrics’ (AAP) policy statement Care Coordination in the Medical Home: Integrating Health and Related Systems of Care for Children with Special Health Care Needs states: “Care Coordination is a collaborative process that links children and families to services and resources in a coordinated manner to maximize the potential of children and provide them optimal health care.” Moreover, this AAP policy statement emphasizes the role of the medical home as a designated care coordinator for successful care coordination.
Goals of care coordination

- Develop an anticipatory/proactive plan for appropriate services for the child and family, integrating the recommendations of multiple professionals and service systems
- Assist the family in accessing needed services and resources
- Facilitate communication among multiple professionals
- Avoid duplication of services and unnecessary costs
- Optimize the physical and emotional health and well-being of the child
- Improve the child’s and family’s quality of life.

As a referral and follow-up methodology is being selected and adapted for the specific organization, it will be necessary to consider care coordination throughout this process. When families enter a system, whether it is a primary care setting, child care setting, or Early Intervention setting, closing the feedback loop and notifying the providers involved with a child is a necessary aspect of successful coordination. The quality of care improves when all providers in the child’s life have the most current information and are notified about the resources and programs that a child and family have accessed.

Coordination considerations

- How is the feedback loop closed?
- What does care coordination mean?
- How can it be achieved at this organization?
- Does the family share all of their information in terms of resources accessed to all providers interacting with their children?
- How can this responsibility be partially or completely alleviated for the family?

The following sections elaborate on each of the components of the care coordination protocol. Some components may be weighed with more consideration than others depending on the needs of the child and family and the capacity of the service provider to provide these components. This framework is meant to be adapted to what will best fit the needs of the families in your community, and the processes at the community level will vary based on the strategies and activities employed.
Establishing the screening procedure

Early identification of developmental disorders is critical to the well-being of children and their families. It is an integral function of the primary care medical home and is an appropriate responsibility of all pediatric health care professionals. Medical homes often use surveillance only to identify developmental disorders. However, screening is recommended by the American Academy of Pediatrics (AAP) as it has been demonstrated to be more useful in identification of developmental concerns.

Surveillance vs. Screening

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<tr>
<th>Surveillance</th>
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<tbody>
<tr>
<td>• Surveillance is a flexible, continuous process whereby knowledgeable professionals perform skilled observations of children during the provision of health care.</td>
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<tr>
<td>• Nearly all pediatric health professionals practice surveillance using their best clinical judgment.</td>
</tr>
<tr>
<td>• Surveillance includes:</td>
</tr>
<tr>
<td>o Eliciting and attending to parental concerns</td>
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<tr>
<td>o Obtaining a relevant development history</td>
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<tr>
<td>o Making accurate and informative observations of children and sharing opinions and concerns with other relevant professionals.</td>
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1Paul Dworkin: Curr Opin Pediatr. 1993; 5:531-536
Screening

- Screening is a brief procedure, using a standardized validated developmental tool, to determine whether a child requires further and more comprehensive evaluation.

- Screenings can and do take place in other environments and medical homes appreciate the opportunity for care coordination when this occurs.

- The AAP produced the statement "Identifying Infants and Young Children with Developmental Disorders in the Medical Home: An Algorithm for Developmental Surveillance and Screening" about developmental screening protocols. This statement provides an algorithm as a strategy to support health care professionals in developing a pattern and practice for addressing developmental concerns for children 0 to 3. Any concerns raised during surveillance should be promptly addressed with standardized screening tools. The AAP recommends that screening tools should be administered regularly at the 9, 18, and 24 (or 30) month visits.

- Tools that are completed by parents, either in the waiting room or outside the office, require less time than some surveillance techniques.

Screening considerations

- Why are you screening—surveillance concern, parental concern, routine well-child visit screening?

- When do you screen?

- For what are you screening (also consider ages for screening purposes)?

- What tool(s) will be used for screening?

- Who works with family to share information about why screening takes place and screening results?

- Who will conduct the actual screening?

- Who will document results, create billing and coding, etc.?

- Who will follow-up with family about results?
Benefits of screening

- Screening using a validated tool is effective.
- Screening tools are an excellent source of information for educating parents. The process helps parents to focus on specific questions they may have about their child’s development.
- Completing the screening tool questionnaire and setting an agenda for discussion jointly at a well-child visit builds the relationships between the parent and child, and also between the parent and the provider. Parents will become more aware of their ability to use you for non-medical concerns.

Communication with Families

Screening for developmental concerns is a way to open the door to conversation not only about health issues in relation to the child, but also developmental and behavioral aspects. Parents may have questions beyond illnesses and immunizations, and screening helps to identify and validate their concerns.

Messaging and communication with families about developmental screening and screening results should be clear, consistent, and direct. What you say to families is as much about style as it is about the specific words.

The authors recommend that all providers who conduct screenings use the following guidelines:

<table>
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<tr>
<th>What do you say to families about why you screen?</th>
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<tr>
<td>- Screening helps all of us as a team to achieve the best outcomes for your child and others in the family.</td>
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<tr>
<td>- Screening can contribute to providing helpful information for families to access services that help young brains develop and grow to their full potential.</td>
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<tr>
<td>- Screening can advance physical and emotional development in children who otherwise might lag behind.</td>
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<table>
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<tr>
<th>How do you talk to families about screening results?</th>
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<tr>
<td>- Find helpful and encouraging words if the screening results are of concern.</td>
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<tr>
<td>- Let families know what will happen next, and who will be contacting them.</td>
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<tr>
<td>- Encourage conversation with family in the office and work with the parents to find helpful ways to communicate with other family members, friends, and</td>
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other support personnel.

- Cultural considerations should include body language, the family's primary language, and spiritual foundation.

Some of the following techniques have proven to be successful in communicating with families in cases when the results indicate the need for further assessment or referral to Early Intervention or community service provider (CSP).

### Techniques for communication with families when there is a need for further assessment or referral.

- Always look at the strengths of the child and of the family.
- Discuss the family’s supports and resiliency.
- Begin by pointing out the child’s positive areas of development or areas of temperament before discussing the areas of concern.
- Parents want to know that you think their child is special, and that the results are not a reflection of their parenting. Find ways to appropriately compliment the parent before addressing the areas of potential concern.

### Remember:

The specific language you use can be very important in setting the tone of the discussion. Think about the language you use for this discussion. Do not assume that it is helpful to the family to use diagnostic language such as “developmental delay.” Instead, find phrases you are comfortable with that prepare the parents for further evaluation. Consider using phrases such as: “children develop differently, and some need extra attention and support during their earliest years. We both want Billy to learn and grow to his full potential, so we need to make sure we know how to support that.” This will allow for a less stressful conversation. Reinforce the idea that the tool you’ve just completed is merely a step in the assessment process, and that the child needs a complete evaluation to look at all aspects of her/his learning and development. Emphasize that the screening tool results are only designed to indicate whether there is a potential issue and that further follow-up may be needed.
BILLING AND CODING PROCEDURE

Developmental screening and referral services are vital to children’s health. Therefore, practices should feel comfortable billing for provision of screening services.

For patients on public aid programs, such as Medicaid and All Kids, the Illinois Department of Healthcare and Family Services (HFS) does reimburse providers for using HFS approved developmental screening tools.

Practices should review their insurance contracts for the applicable developmental screening codes to see what private insurance carriers will reimburse.

Developmental Screening Tools ²

Screening tools for developmental testing; limited, with interpretation and report, CPT code 96110, approved by HFS include:

Ages and Stages Questionnaires (ASQ)
Ages & Stages Questionnaire 3rd Edition (ASQ-3)
Ages & Stages Questionnaires: Social-Emotional (ASQ: SE)
Battelle Developmental Inventory Screening Test (BDIST)
Bayley Infant Neurodevelopment Screener (BINS)
Bayley Scales of Infant and Toddler Development 3rd Edition (Bayley-III) – Screening Test
Brief Infant Toddler Social and Emotional Assessment (BITSEA)
Brigance Early Childhood Screens (0-35 Months, 3-5 Years, K&1)
Chicago Early Developmental Screening Inventory
Developmental Profile II
Developmental Indicators for the Assessment of Learning – Revised (DIAL-R)
Developmental Indicators for the Assessment of Learning – 3rd Edition (DIAL-3)
Early Language Milestone Scales Screen
Early Screening Inventory (ESI)
Early Screening Profiles (ESP)
Eyberg Child Behavior Inventory/Sutter-Eyberg Student Behavior
Family Psychosocial Screening
Infant Development Inventory (IDI)
Infant -Toddler Checklist for Language and Communication
Infant-Toddler Symptoms Checklist
McCarthy Screening Test (MST)
Modified Checklist for Autism in Toddlers (M-CHAT)

² January 2015 Handbook for Providers of Healthy Kids Services Appendix HK-16
Minneapolis Preschool Screening Instrument (MPSI)
Parent’s Evaluation of Developmental Status (Peds)
Parent’s Evaluation of Developmental Status- Developmental Milestones (Peds:DM)
Parents’ Observation of Infants and Toddlers (POINT)
Pediatric Symptom Checklist (PSC)
Project Memphis DST
Revised Developmental Screening Inventory
Revised Parent Developmental Questionnaire
Safety Word Inventory and Literacy Screener (SWILS)
Temperament and Atypical Behavior Scale (TABS) Screen

Since the list may change as tools are added or removed, it is recommended to check the Handbook for Providers of Health Kids Services (HKHandbook) appendices for a comprehensive list of HFS approved tools.

**Developmental Evaluation Tools**³

Developmental evaluation is performed when results of screening indicate a more detailed evaluation is needed or when high-risk conditions (e.g. prematurity) are present. Evaluation tools which are defined in the CPT as developmental testing; extended, with interpretation and report, (e.g., includes assessment of motor, language, social adaptive or cognitive functioning by standardized developmental instrument), **CPT code 96111**, that have been approved by HFS include:

Achenbach Child Behavior Checklist – Preschool Module (ASEBA)
Battelle Developmental Inventory (BDI)
Bayley Scales of Infant and Toddler Development III
Brigance Inventory of Early Development III Standardized (IED III)
Child Development Inventory (CDI)
Connor’s Rating Scales (CRS)
Developmental Assessment of Young Children (DAYC)
Devereux Early Childhood – Clinical Form
Devereux Early Childhood Assessment for Infants and Toddlers
Early Coping Inventory
Erhardt Development Prehension Assessment (EDPA)
Hawaii Early Learning Profile (HELP)
Infant Toddler Developmental Assessment (IDA)
Infant-Toddler Social and Emotional Assessment (ITSEA)
Otis-Lennon School Ability Test (OLSAT)
Piers-Harris Children’s Self-Concept Scale (PHCSCS)
Temperament and Atypical Behavior Scale (TABS) Assessment Tool

³ January 2015 Handbook for Providers of Healthy Kids Services Appendix HK-16
Vineland Adaptive Behavior Scales (VABS)
Vineland Social-Emotional Early Childhood Scales (Vineland SEEC)
Vineland Social Maturity Scale

Since the list may change as tools are added or removed, it is recommended to check the *Handbook for Providers of Health Kids Services* (HKHandbook) appendices for a comprehensive list of HFS approved tools.

*The purpose of the inclusion of the evaluation tools in this toolkit is to remain consistent with the HK Handbook narrative. While this toolkit is about screening, it is primarily about care coordination with Early Intervention. Primary Care Providers should be encouraged to not only refer if there is evidence of concern when using a screening tool (96110), but also if there was sufficient concern that the provider used an evaluation tool (96111).*

**Reimbursement**

In order to be reimbursed for using a screening or evaluation tool, providers must bill under the proper CPT code, maintain the tool and document results in the child’s medical file for auditing purposes. Anticipatory guidance and referrals made as a result of the screening shall be documented. Providers billing at an encounter rate, such as Federally Qualified Health Centers (FQHCs), Rural Health Clinics (RHCs), and Encounter Rate Clinics (ERCs) will not receive a separate reimbursement, but must detail the objective developmental screening or evaluation performed on the encounter claim.\(^4\)

\(^4\) January 2015 *Handbook for Providers of Healthy Kids Services* HK-203 (21)
ESTABLISHING THE REFERRAL PROCEDURE

Remember:
After a child has been screened for developmental delay and if you have concerns about the screening results, the next step is to refer that child and family to the appropriate resources or programs that will best meet their identified needs.

When implementing a referral process, several of the issues to consider include:
- Creation of the procedure for referral within the practice.
- Use of a referral form for documentation and follow-up
- Additional available resources in the community for families

This referral process varies across systems and organizations and is part of the larger care coordination protocol. Some of the initial referral procedure questions include who is going to make the referral, where will the patient and family be referred and who contacts the referral source to access the service(s).

<table>
<thead>
<tr>
<th>Referral process considerations within the practice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Who is responsible for making the actual referral?</td>
</tr>
<tr>
<td>Who contacts the resource to determine their referral procedure, availability, and eligibility in order for the family to access services?</td>
</tr>
<tr>
<td>What must the provider/service coordinator/staff member do to effectively refer a family to a community resource?</td>
</tr>
<tr>
<td>Who in the organization documents information on the referral form?</td>
</tr>
<tr>
<td>Who in the organization will work with the referral source to follow-up and share information?</td>
</tr>
<tr>
<td>What resources exist in the community to send families to?</td>
</tr>
<tr>
<td>Does our organization have a relationship with enough resources in the community to meet the needs of our families through a referral process?</td>
</tr>
</tbody>
</table>
How do we track our relationships with referral sources?

- Where is the resource inventory? Is it a database in a computer or is it merely a paper binder or a paper resource list? Is it easily accessible?
- Who oversees this process? Is there the capability for staff oversight of this referral process and resource inventory?

Medical Home Team Responsibilities

If a practice is not already doing so, it is important to designate a staff member to coordinate referrals and follow-up with families whether referring to Early Intervention or special education (SPED) in order to make sure there is appropriate and timely follow through. Many designated referral coordinators call the referred agency and fax the referral to that agency, in addition to giving that referral to the family. It is also important to develop a protocol to document the referral process for the benefit of the family.

**Champion:** One or two professional staff members who take the lead in promoting and implementing the care coordination protocols in the practice. Champions believe in the value of and see the need for a care coordination protocol.

**Care coordinator:** The individual responsible for managing the care coordination protocol of the medical home. Most practices do not have the means of having one care coordinator handle the entire care coordination protocol and create plans that assign specific staff members to take on appropriate responsibilities as part of the office’s care coordination protocol. The team can determine in advance which team member can best take responsibility for making the system run smoothly. Various team members can prepare materials for distribution, provide basic guidance to families on how to complete the tools, collect completed materials, score the tools, and provide routine feedback to families of children who are not identified as requiring further assessment. They may also distribute age appropriate developmental materials to families as part of the practice’s patient education procedures as well as maintain and update lists of local service providers and specialists that all the practice staff need to make referrals. Some suggested assignments and staff designations follow;

**Medical records staff** can prepare charts prior to the office visit and pull and insert the appropriate screening tool. They will need to know the age of child and the practice’s guidelines for which screening test to use at which visit. They may need to calculate for prematurity in some cases.

**The receptionist** is often the first person who families see when they enter the practice and is the first person to greet families. The receptionist should be able to offer the family the tool and explain its purpose in a manner that makes them feel comfortable and does not alarm them. The receptionist will also ask the parent or caregiver if she
needs assistance completing the screening tool. This might involve assessing the state of the waiting area, or noting how many other children the parent has brought and if that might affect her ability to complete the screening tool. The front office staff will need training in how to offer assistance; for instance, asking “Would you like to complete the form on your own or have someone go through it with you?”

**Medical assistants** could be involved in scoring the tools. They will need to understand each screening test used in the practice and the techniques for proper scoring.

**Registered nurses** can be involved in screening, scoring, and discussing child developmental and behavioral concerns with caregivers, particularly when the tests show that the children are developing normally and guidance focuses on basic parenting and supports. They can also help with referrals to community resources.

**Physicians, nurse practitioners, and physician assistants** should be involved in reviewing all completed tools. They should also help monitor scoring to ensure that red flags and items with multiple interpretations are addressed. When indicated, the physician, nurse practitioner or physician assistant would also be the staff member to administer a follow up screening. These medical professionals should also discuss results and concerns with families and make appropriate referrals to community resources and plan for a follow-up appointment.

**Clerical staff** is key when ordering, reproducing and re-ordering supplies. They will need to maintain master copies and have a handle on how many copies a practice will need for the following month. They will formulate the plan for where to store materials and how to distribute and collect the materials.
Example of Medical Home Team Responsibility

<table>
<thead>
<tr>
<th>Team Member</th>
<th>Responsibility</th>
</tr>
</thead>
<tbody>
<tr>
<td>Champion</td>
<td>• Lead in promoting and implementing the care coordination protocols in the practice</td>
</tr>
<tr>
<td>Care coordinator</td>
<td>• Responsible for managing the care coordination protocol of the medical home</td>
</tr>
<tr>
<td>Medical records staff</td>
<td>• Prepare chart prior to office visit, insert appropriate screening tool(s)</td>
</tr>
<tr>
<td>Receptionist</td>
<td>• Offer families the screening tool form(s), explain purpose</td>
</tr>
<tr>
<td></td>
<td>• Offer assistance with completing form</td>
</tr>
<tr>
<td>Medical assistants</td>
<td>• Score the screening tools form(s)</td>
</tr>
<tr>
<td>Registered nurses</td>
<td>• Involve in screening, scoring, and discussing child developmental/behavioral concerns with caregivers</td>
</tr>
<tr>
<td></td>
<td>• Offer assistance with referrals to community resources</td>
</tr>
<tr>
<td>Physicians, nurse practitioners and physician assistants</td>
<td>• Responsible for reviewing all completed forms</td>
</tr>
<tr>
<td></td>
<td>• If necessary, administer follow-up screening</td>
</tr>
<tr>
<td></td>
<td>• Discuss results and concerns with families</td>
</tr>
<tr>
<td></td>
<td>• Make appropriate referrals to community resources</td>
</tr>
<tr>
<td></td>
<td>• Plan for a follow-up appointment</td>
</tr>
<tr>
<td>Clerical staff</td>
<td>• Order, reproduce, reorder supplies</td>
</tr>
<tr>
<td></td>
<td>• Formulate a plan on where to store materials and how to distribute and collect materials</td>
</tr>
</tbody>
</table>

Because of the variance in practice staff capacity, each practice is encouraged to create their own table of responsibilities assigned to each staff member. The authors have included a copy of this example of medical home team responsibilities in Appendix E.
EARLY INTERVENTION

Early Intervention as a developmental model is a federally mandated, federally and state funded program that provides assessment, therapeutic services and service coordination for children. They serve children birth to age 36 months who have a medical diagnosis that predicts delay, or are considered to be at risk for developmental delay. The Early Intervention System is the system that implements Part C of IDEA in Illinois and the Illinois Early Intervention Services Act. The program is implemented through DHS. The Child and Family Connections offices are the entry point into the Early Intervention program in Illinois. There are 25 Child and Family Connections offices in Illinois that can be found by searching the DHS Office Locator on-line search tool.

When to Refer Children to Early Intervention

Eligibility Criteria
Children residing in Illinois who are under the age of three years and their families are initially eligible for Early Intervention services if written evaluation/assessment reports completed by a multidisciplinary team confirm that the child:

- Has a developmental delay; or
- Has a physical or mental condition which typically results in developmental delay; or
- Is at risk of having substantial developmental delays, according to informed clinical judgment.

Developmental Delay
“Developmental delay” means DHS determined eligible level of delay (30% or greater) in one or more of the following areas of childhood development: cognitive; physical, including vision and hearing; language, speech and communication; social-emotional; or adaptive self-help skills. The eligible level of delay must have been:

- Measured by DHS approved diagnostic instruments and standard procedures; or
- Confirmed through informed clinical judgment of the multidisciplinary team if the child is unable to be appropriately and accurately tested by the standardized measures available.

Activities used to determine eligibility whether using a diagnostic instrument or clinical judgment that development of an eligible level of delay (30% or greater) is probable if Early Intervention services are not provided shall also include clinical observation of the child, parent report, identification of the child’s unique strengths and needs in the area(s) that are being tested and a review of the child’s medical, educational or other records. This information shall be described in the required written evaluation/assessment report to be submitted in a DHS determined report format.
Medical Conditions Resulting in Developmental Delay

“Physical or mental condition which typically results in developmental delay” means a medical diagnosis:

- Approved by DHS as an eligible condition (see the following list of Medical Conditions Resulting in High Probability of Developmental Delay); or
- Confirmed by a qualified family physician, pediatrician or pediatric sub-specialist as being a condition with a relatively well-known expectancy for developmental outcomes within varying ranges of developmental disabilities. Pediatric sub-specialists included are those such as pediatric neurologists, geneticists, pediatric orthopedic surgeons and pediatricians with special interest in disabilities. If a child exhibits a medical condition not approved by DHS as being an eligible condition, the qualified multidisciplinary team may use written verification by one of the physician categories identified above that the child’s medical condition typically results in substantial developmental delay within the varying ranges of developmental disabilities.

Clinical Opinion

At risk of substantial developmental delay, according to informed clinical opinion means the multidisciplinary team confirms that development of a DHS determined eligible level of delay (30% or greater) is probable if Early Intervention services are not provided because the child is experiencing either:

- A parent who has been medically diagnosed as having a severe mental disorder as set forth under axis I and axis II of the Diagnostic and Statistical Manual 5 (DSM 5) or a developmental disability; or
- Three or more of the following risk factors:
  - Current alcohol or substance abuse by the primary caregiver;
  - Primary caregiver who is currently less than 15 years of age;
  - Current homelessness of the child. Homelessness is defined as children who lack a fixed, regular and adequate nighttime residence, in conformity with the McKinney Vento Homeless Assistance Act;
  - Chronic illness of the primary caregiver;
  - Alcohol or substance abuse by the mother during pregnancy with the child;
  - Primary caregiver with a level of education equal to or less than the 10th grade, unless that level is appropriate to the primary caregiver’s age;
  - An indicated case of abuse or neglect regarding the child and the child has not been removed from the abuse or neglect circumstances.

Timeline for Referral to Early Intervention

According to federal law, once a care provider identifies a developmental concern, the patient has the right to be referred to the appropriate agency within 7 days, however Illinois has adopted in Administrative Code requiring the referral to be sent within 5 business days. Once the patient is referred, the agency is required to initiate contact
within 2 business days. With consent, the agency must evaluate and assess the patient and determine his or her eligibility for specific programs and services.

If the child is determined eligible for Early Intervention services, Early Intervention must then work with the families of the eligible child to formulate a service plan within 45 calendar days after the referral has been received. This is called an Individual Family Service Plan, or an IFSP. This plan is reviewed for progress every year with opportunities for additional review sooner.

**Services Early Intervention Provides**

Early Intervention services are intended to:

- Improve function
- Promote social competence and integration
- Enable families to understand their children’s needs, so they can better prepare for the future, and prevent unnecessary secondary disabilities

**How to Make a Referral to Early Intervention**

A successful referral to Early Intervention requires the use of documentation such as the [Standardized Illinois Early Intervention Referral Form](#) to standardize the referral process between the referring agency and the Child and Family Connections (CFC) office. A standardized form increases the accuracy and pace of the referral to Early Intervention, enhances communication among the medical home, the CFC, and the family, and gauges the family’s experience and ability to follow-up on a referral.

The needed parent/guardian consent that meets both Health Insurance Portability and Accountability Act (HIPAA) and Family Educational Rights and Privacy Act (FERPA) requirements are built into this form, which expedites effective information exchange. Not only does this consent authorize the referring agency to share information with Early Intervention, it also authorizes Early Intervention to share eligibility determination information back to the child’s medical home as well as the referring agency.

The [Standardized Illinois Early Intervention Referral Form](#) can be found on HFS’ web site or refer to Appendix C of this toolkit.

A list of the 25 CFC offices in Illinois can be found at the DHS [Office Locator](#) or in Appendix D of this toolkit.

Using this form, the medical home can identify:

- Information about the child
- Why the referral was made
- The referring party (in this case the medical home)
- To whom the referral was made (which CFC)
Communication with Families When Making a Referral to Early Intervention

When it is determined that a child should be referred to Early Intervention, you want to ensure that the family understands that their child may be able to benefit from early intervention services. Therefore it is important to briefly explain what Early Intervention is and what services are offered. We say “briefly” because families may not be able to “hear” what you tell them. You should find time to expand upon information as families ask questions.

<table>
<thead>
<tr>
<th>What do you say to families about why a referral is being made?</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Early Intervention supports families in promoting their child’s optimal development.</td>
</tr>
<tr>
<td>• Early Intervention improves family adaptation for the child and their ability to function within the family unit.</td>
</tr>
<tr>
<td>• Early Intervention helps socially disadvantaged children and improves outcomes in children with underlying biological conditions.</td>
</tr>
<tr>
<td>• When Early Intervention is used, a child may require fewer services later in life.</td>
</tr>
</tbody>
</table>

It is important that everyone involved in the child’s care is kept aware of what is going on. This form helps to do that. When further evaluation is needed, the form documents all that has been done so far.

<table>
<thead>
<tr>
<th>What do you say to families about the referral process including documentation?</th>
</tr>
</thead>
<tbody>
<tr>
<td>• The standardized referral form serves as a tracking tool for where in the process the child is, so that all parties involved can track each step of the process.</td>
</tr>
<tr>
<td>• The standardized referral form serves to keep the medical home informed of services the child has been referred to, and enables the medical home to support the family</td>
</tr>
</tbody>
</table>
Determining which Early Intervention Location is Appropriate for the Family

The Child and Family Connections offices are the entry point into the Early Intervention program in Illinois. There are 25 Child and Family Connections offices in Illinois that can be found by searching the DHS Office Locator on-line search tool. Which CFC office to refer to is determined by the family’s residential county or zip code (if the family resides in Cook County).

What Happens after the CFC Receives a Referral?

Once the CFC receives the Standardized Illinois Early Intervention Referral Form, the CFC service managers will assign the family to a CFC service coordinator. CFC coordinators assist families in obtaining screenings and evaluations to determine eligibility for the Early Intervention program, assess service needs of eligible children, plan for needed services, and choose credentialed providers.

The CFC shares information about the referral back to the medical home using the Illinois Early Intervention Referral Fax Back Form [pdf]. A copy of this form can also be found in Appendix C. This form will let the medical home know if:

- The CFC was able to establish contact with the family
- A Service Coordinator has been assigned to the family
- The family has declined services
- The child has been evaluated and found to be not eligible for services
- The child has been evaluated and found to be eligible for services
- The child and family have been recommended to receive Early Intervention services (and will indicate what type)
- An IFSP was/will be developed for the child and family
- The child and family received referrals to non-Early Intervention services

REMEMBER:
Section 6 of the Standardized Illinois Early Intervention Referral Form authorizes the CFC to release information back to the primary care provider and/or referring agency (using the Illinois Early Intervention Referral Fax Back Form) in compliance with HIPAA and FERPA requirements.
Providing the Family with Helpful Guidance after a Referral is Made

If possible, provide the parents with guidance on what they can do at home before their next visit to your office, or to the specialist or Early Intervention office to whom you refer them. Often, this may be as simple as suggesting that they read to or play (using specific skill tools) with their child with intentionality. This may help them feel more empowered as parents and alleviate some of the vulnerability they might be experiencing. This guidance will be particularly important if the child is not eligible for Early Intervention services but has developmental delays nonetheless. Your initial guidance to the parents can empower them and change the course of their child’s development for years to come.

<table>
<thead>
<tr>
<th>Guidance chart</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Look and listen for signs that the parent will be reluctant to share information with her/his partner, parents or other relatives, or friends.</td>
</tr>
<tr>
<td>• Work with the family to create verbiage about what they might tell others in order to provide useful information to those who might offer helpful support if they correctly understand the situation.</td>
</tr>
<tr>
<td>• Acknowledge family fears and anticipate that the family might have “cold feet,” thus avoiding your recommendations for referral and further assessment. There are many reasons why parents fail to follow through on referrals.</td>
</tr>
<tr>
<td>• Understanding their reluctance and taking a non-judgmental approach to working with them further may allow you to address their issues.</td>
</tr>
<tr>
<td>• Encourage communication. Tell the parents that if they decide against further evaluation you would like to be informed.</td>
</tr>
<tr>
<td>• Always provide the parent with as much information on the referral process and resource as you can. Phone numbers, descriptions of the referral service or provider, and written documentation of the screening results are crucial.</td>
</tr>
<tr>
<td>• ICAAP recommends that the medical home have a representative contact the family within 36 office hours after providing information and referral recommendations to offer support and encouragement.</td>
</tr>
<tr>
<td>• Consider a follow-up appointment after the evaluation to discuss the results and offer additional support.</td>
</tr>
</tbody>
</table>

**Remember:**

As a service provider, the more information you give families about the referral process, the more you can demystify the process for them, empower them to participate in the process, and encourage communication between the family and the medical home.
Referral Follow-up Process Flowchart for Early Intervention and Special Education (SPED)

- **Identification**
  - 5 working days

- **Referral for Evaluation and Assessment (service coordinator assigned)**
  - 45 calendar days for EI

- **Evaluation/Assessment**
  - Eligibility Determined
    - IFSP Developed
    - IEP Developed
    - 60 school days for SPED

**Remember:**

Only the parent/guardian can request SPED evaluation from the school district.
ADDITIONAL REFERRAL RESOURCES

There are many local and statewide programs that promote a child’s healthy development. Based on the patient’s developmental status and age, patients may be referred to Early Intervention, Special Education, or other prevention programs.

Statewide Provider Database

The Illinois Department of Children and Family Services (DCFS) Statewide Provider Database (SPD) is an online database with comprehensive information on service agencies and programs throughout Illinois. The SPD was developed to assist caseworkers in identifying and locating appropriate services for their clients. SPD contains information on services that are open to all children and families. SPD saves you time by searching all the available resources for the closest provider that offers the service you are looking for. Each program location in the SPD is assigned a geocode, which allows SPD users to search for services by distance from a client’s location. The SPD is located at the DCFS Welcome to the Illinois Outcomes web site. DCFS employees can contact the DCFS helpdesk at 800-610-2089 to get access to the SPD. Non-DCFS employees can contact Erik Sandberg at Erik.Sandberg@illinois.gov to get access to the SPD.

Special Education

Special Education (SPED) is provided through the school system for children ages 36 months to 21. Children receive appropriate educational and therapeutic services mandated by Individuals with Disabilities Education Act, or IDEA. The responsibility for providing these services falls to the local public school district.

Only the child’s parent or guardian can request that a child be assessed for SPED. Special education programs are administered by local school districts. Each school district must develop and make known to all concerned persons, the procedures through which an evaluation may be requested. Each local school district is required to make known to families in writing the specific process for requesting an assessment.

When to Suggest the Family Request Children be Assessed for SPED

If the child is 36 months to 5 years of age, the child should be referred for a special education evaluation. There are specific disabilities and special education categories,
and each of these will come with different services provided by the school. The school district will focus on those disabilities that hinder learning.

Once a child is determined to need SPED services, families with children 36 months or older work with their local Special Education programs to formulate a service plan called the Individualized Education Plan, or IEP.

For additional information about family rights related to SPED, please see the Special Education Services Patent Rights web site.

Referral Follow-up Process Flowchart for Early Intervention and SPED

Remember:
Only the parent/guardian can request SPED evaluation from the school district.
Examples of Prevention Programs

Prevention programs are for children at risk of developmental delay. These programs can help children and their families develop to their fullest potential and help parents with the challenges in their lives as well. These programs provide services for children and parents and do not require a referral. However, you and your organization may be in a unique position to recommend that a family pursue connection with a prevention program.

Head Start/Early Head Start:
Eligibility for Early Head Start and Head Start is based on the U.S. Department of Health and Human Services (HHS) Poverty Guidelines. To learn more about these guidelines, please log on to the HHS Poverty Guidelines, Research, and Measurement website. To locate Early Head Start/Head Start programs in your area, please see the Head Start Locator on the Early Childhood Learning and Knowledge Center.

Home Visiting Programs:
- **Early Head Start (EHS) Home-Based Model**
  EHS Home-Based Model provides high-quality, culturally competent child development and parent support services with an emphasis on the role of the parent as the child’s first, and most important relationship.

- **Healthy Families Illinois (HFI)**
  HFI is a voluntary, intensive home visiting program that reduces family isolation, supports parents as children’s first teachers and caretakers, and helps parents develop good parenting skills. Access the DHS Healthy Families Illinois Provider List to identify providers by county.

- **Nurse-Family Partnership (NFP)**
  NFP is an evidence based community health program that helps transform the lives of vulnerable mothers pregnant with their first child. Each mother served by NFP is partnered with a registered nurse early in her pregnancy and receives ongoing nurse home visits that continue through her child’s second birthday.

- **Parents As Teachers (PAT)**
  PAT is a home-based family education and support program. Through this program, parents acquire skills that help them make the best of children’s crucial early learning years.

For information about referring a family to a Maternal, Infant and Early Childhood Home Visiting (MIECHV) program, see the Home Visiting Providers section of this toolkit.
The Autism Program

The Autism Program (TAP) of Illinois offers a network of resources for Autism Spectrum Disorders (ASDs) in the State of Illinois. TAP provides the strategy and framework for the State of Illinois to address the complex issues involved in diagnosis, treatment and research for the thousands of children in Illinois with ASDs.
FOLLOW-UP PROCEDURE

After a referral has been made for the child it is ideal to have a follow-up procedure in place to determine if the referral was executed.

### Follow-up questions

<table>
<thead>
<tr>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>Was the family able to connect with the referral source for services?</td>
</tr>
<tr>
<td>Did the family seek services from another source?</td>
</tr>
<tr>
<td>Did the family decide not to follow through on the referral?</td>
</tr>
<tr>
<td>What was the medical home response?</td>
</tr>
</tbody>
</table>

Implementing a follow-up procedure will aid in determining whether the family called the referred agency, accessed services, and will allow the organization to support the family and observe the success in accessing services. When identifying the process to be used to follow-up and document the referral process, it is important to think through an effective process that will enable the medical home to determine whether the family actually accessed the services or program.

### What is the process to determine if the family accessed the services or program?

<table>
<thead>
<tr>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is there a staff person who calls the family to check to see if they were able to access services?</td>
</tr>
<tr>
<td>Does the program or resource accessed by the families communicate with the original referral source to notify that the family accessed services?</td>
</tr>
<tr>
<td>How can this feedback loop be closed? Does the family have to authorize the closing of this feedback loop?</td>
</tr>
<tr>
<td>Is this a responsibility of the family? Should they call back if they were unable to access services? Who should be charged with this responsibility?</td>
</tr>
</tbody>
</table>

Of equal importance is determining the documentation process needed to improve referrals in the future. The following key questions should be considered when determining the documentation aspect of the referral and follow-up methodology.
How is this documented?

- Is this documented on the referral form?
- Who is documenting this process? Where does the responsibility fall?
- Can there be an identified individual or group of individuals to document this process?

Open and transparent communication is an essential characteristic within these components. In a genuinely coordinated system, providers receive confirmation that referrals were completed as well as important information such as any follow-up testing or follow-up services. Creating this feedback loop allows all service providers who interact with a particular family to know where the family is at and whether they need additional assistance and services. Research indicates that generally it takes an average of four community-based referrals before the “right” referral is found for the family. The Statewide Provider Database (SPD) is an online database that can help you identify and locate appropriate services for your clients, and contains comprehensive information on services that are open to all children and their families. More information about accessing the SPD can be found in the glossary under Appendix A. Providing suitable and helpful referrals necessitates clear, cohesive, and on-going communication among service providers and the family, an appropriate assessment of the family’s needs, and an ongoing relationship with the family to determine the most useful resources for referral.

One of the lessons learned from previous care coordination work is that families will very quickly talk with other family members, close friends, and those who offer support such as clergy about “what the doctor said”. They will have made a decision about whether to follow up on the referral within a very short period of time after these conversations. Medical homes may want to have some additional input into the family’s decision making in a non-threatening and non-authoritarian way. The authors recommend the following procedure and messaging:

*Within 36 hours of making referral, designated practice staff will make a follow up phone call to families of the above identified children to offer encouragement and support and confirm and document family’s intent to use the referral*
MONITORING & EVALUATION FOR THE MEDICAL HOME

Once your organization has implemented the Care Coordination Protocol, monitoring and evaluation will provide the organization with feedback on how this process is working and how it can be improved. Although monitoring and evaluation are grouped in the same component of this framework, they are technically two separate pieces. The purpose of monitoring is to identify the fluidity of the referral and follow-up methodology as well as to improve any flaws or potential issues with the referral process. This is an internal monitoring or audit to identify any gaps and challenges with the procedural framework at the organization. Evaluation is the actual measurement of the program. Utilizing performance measures, the referral and follow-up methodology are being assessed in terms of structure, process, and outcomes.

<table>
<thead>
<tr>
<th>Monitoring &amp; evaluation questions to consider</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Is there a system to identify and understand the various gaps and barriers in the model?</td>
</tr>
<tr>
<td>• How is the system being monitored internally to make sure that families are being referred successfully?</td>
</tr>
<tr>
<td>• Are there specific and targeted gaps in service that could improve the referral and follow-up process?</td>
</tr>
<tr>
<td>• How is the referral and follow-up process being measured? What performance measures are being utilized?</td>
</tr>
</tbody>
</table>

Maintenance of Certification Part 4 (MOC4) Process and Medical Home Expectations

Using the P-D-S-A (Plan-Do-Study-Act) model, the objective of the Maintenance of Certification Part 4 process is for a practice to create a patient-centered approach to improving care coordination for children aged birth to three. This includes regular developmental screenings of 9, 12, and 18-month olds*, using a validated screening tool, and referrals to Early Intervention for assessment, via use of a standardized referral form to be faxed to the Child and Family Connections (CFC) office.

*The recommended periodicity screening at 9, 12, and 18 months is specific to the American Board of Pediatrics (ABP) MOC4 process. The periodicity recommended by the American Academy of Pediatrics (AAP) and HFS is at 9, 18, 24 and 30 months.
The PDSA Model for Improvement Cycle uses four keys to implement positive change in an organization: **Plan - Do - Study - Act.**

It asks the questions: What are we trying to accomplish? How will we know that a change is an improvement? What change can we make that will result in improvement?

**Plan:** Make a decision to carry out the cycle,

**Do:** Document problems and observations,

**Study:** Compare data to predictions, summarize learning,

**Act:** Examine what changes are to be made, determine what is next.
If seeking to attain MOC4, physicians are expected to participate in two web based trainings (on care coordination and developmental screening and referral, both for CME) which can be accessed on the [Enhancing Developmentally Oriented Primary Care (EDOPC)](http://www.edopc.org) website. EDOPC is a partnership of the Advocate Health Care Healthy Steps Program and the Illinois Chapter of the American Academy of Pediatrics (ICAAP). EDOPC worked to improve the delivery and financing of preventive health and developmental services for children birth to three. Building on existing programs, such as the Healthy Steps model, a range of strategies were developed that primary care settings can implement to effectively provide comprehensive developmentally oriented health care. Visit the [EDOPC Register for Free Online Training](http://www.edopc.org/register) registration page to learn more about the trainings and to get started.

### Documenting your Progress

There are various reporting forms that have been developed to assist the practice in fulfilling the obligations of the MOC4 process. Activity forms or Run Charts, Standardized Referral Forms, Fax Back Forms and Chart Review forms will documents each step of the referral process for every patient who is screened and referred for services (Early Intervention, SPED, community service provider, etc.). These activity forms can be found in Appendix E. In this way the practice can be sure they are kept in the feedback loop and are able to offer appropriate family support and care coordination.
Determining your Success

When implementing the screening and documentation process, the practice has the opportunity to evaluate the procedure used in their own office, and determine if changes need to be made. Appropriate use of the tracking forms, as well as following all the steps from screening to referral, will help the practice to be truly helpful to their patients and their families.
Home Visiting Providers

Introduction

A home visiting program has many benefits for all involved. It assists a medical home to provide more comprehensive care to a family, the home visitor can better communicate the family's health needs and risk factors to the medical home, and the family has expanded opportunities for access to other important services and supports.

American Academy of Pediatrics (AAP) Policy Statements

The AAP, in its policy statement, The Role of Preschool Home Visiting Programs in Improving Health and Developmental Outcomes (February 2009), recommends that pediatricians should become aware of and participate in development of home-visiting programs in their communities. It also states that there is ample reason to believe that the synergy of home visitors working with pediatric clinicians could have positive effects on child health and development, and calls for free flowing communication between home visitors and pediatricians. However, the statement also notes that while appeals for home visiting linked to well-child care have been frequent, the "how" and "why" of these linkages are poorly defined and require additional investigation. Given its strong work in early childhood to date, Illinois is poised to help answer these questions and contribute to national best practices.

The AAP policy statement, The Medical Home (July 2002, reaffirmed in 2008), recommends that comprehensive health care for infants, children, and adolescents should (also) include "interaction with early intervention programs, schools, early childhood education and child care programs, and other public and private community agencies to be certain that the special needs of the child and family are addressed."

Executive Summary

For the past decade, increased emphasis has been placed on directing public investments toward programs with the strongest evidence base. This has been particularly true in the area of home-based interventions targeting pregnant women, families, and their young children. The Maternal, Infant and Early Childhood Home Visiting (MIECHV) program, authorized by the Patient Protection and Affordable Care Act of 2010 [pdf] (see pages 216-225), facilitates collaboration and partnership at the federal, state and community levels to improve health and development outcomes for at risk children through evidence based home visiting programs.
MIECHV is designed to use evidence based home visitation as a strategy to:
1. Strengthen and improve the programs and activities carried out under the Title V Maternal and Child Health Program
2. Improve coordination of services for at risk communities
3. Identify and provide comprehensive services to improve outcomes for families who reside in at risk communities

Targeted participant outcomes include:
- Improved maternal and child health
- Prevention of child injuries, child maltreatment, and reduction of emergency department visits
- Improvement in school readiness and achievement
- Reduction in crime or domestic violence
- Improvements in family economic self-sufficiency
- Improvements in the coordination and referrals for other community resources and supports

Which communities are participating in the Illinois MIECHV program?
1. Englewood, West Englewood, and Greater Grand Crossing
2. Cicero Township
3. City of Elgin
4. City of Rockford
5. Macon County
6. Vermilion County

What is the fee to families for participating in the MIECHV home visiting program?
A home visiting program uses trained home visitors to provide direct services to pregnant women or children from birth to age 5. Home visiting services are free and voluntary. There are NO charges for the services, and families can choose to accept or decline these services. All home visiting services are confidential.

What is an evidence based home visiting program model?
An evidence based home visiting program model is one that is based on theory and has shown a positive effect on child development. The MIECHV evidence based home visiting program models used in Illinois are:
- **Home-based Early Head Start** (EHS) – serving low-income pregnant women and families with children from birth to age 3.
- **Healthy Families Illinois** (HFI) – serving at risk families with children from birth to age 5.
- **Nurse-Family Partnerships** (NFP) – serving first time low-income mothers from pregnancy until the baby turns two.
- **Parents as Teachers** (PAT) – serving families with children from birth to age 5.
What happens during a MIECHV home visit?
The home visitor provides education about topics that each family helps select, and ideas about activities and interactions that parents may want to try with their children. The home visitor will model activities with parents and their children to stimulate attachment and development. Each visit lasts about an hour. The scheduling of home visits (weekly, bi-weekly or monthly) depends on each family’s situation and the home visiting program model that is being used. Visits are planned in advance, in coordination with the family’s schedule.

Additional services that are included as part of MIECHV
Home visitors will work with families to connect them to services that address their needs, such as parenting classes, support groups, health care services, counseling, child care and preschool, or developmental services. The goal for home visiting is to serve as a central hub that connects families to a comprehensive range of early childhood services.

In Illinois, each funded MIECHV community collaboration includes a Coordinated Intake agency, and several agencies that provide evidence based home visiting services to at risk families. These agencies include county health departments, school districts and community-based social service agencies.

About MIECHV Home visitors
MIECHV Home visitors are professionals or paraprofessionals who have received background checks and have experience related to child development and family strengthening. They have also received extensive training in their agency’s home visiting model as well as core knowledge and skills relating to domestic violence, substance abuse, developmental disabilities and maternal depression. MIECHV home visitors, in the course of their work with families, complete the following screenings and refer families for services as indicated:

- 4P’s Plus (substance abuse screening)
- Relationship Assessment Tool (domestic violence screening)
- Edinburgh Assessment (maternal depression)
- ASQ-3 Assessment (child cognitive development)
- ASQ-SE Assessment (child socio-emotional development)

About the Coordinated Intake worker (CIW)
Coordinated Intake workers serve as the hub for intake for new families. There are several different models for coordinated intake. In most cases, coordinated intake workers conduct outreach to families and complete the Coordinated Intake Assessment Tool (CIAT), which collects program eligibility information before referring families to an appropriate home visiting program.
Medical Home Referral to a MIECHV Home Visiting Program

To initiate the process for referring a family to a home visiting program, please identify the local office by using the online Coordinated Intake Office Contact Information [pdf] and using the Medical Home Referral Form to Coordinated Intake Office [pdf]. The Coordinated Intake office will share the referral outcome with the medical home using the MIECHV Coordinated Intake Office Referral Fax Back Form [pdf].

Referring to Early Intervention

A successful referral to Early Intervention requires the use of documentation such as the Standardized Illinois Early Intervention Referral Form to standardize the referral process between the referring agency and the Child and Family Connections (CFC) office. A standardized form increases the accuracy and pace of the referral to Early Intervention, enhances communication among the medical home, the CFC, the home visitor and the family, and gauges the family’s experience and ability to follow-up on a referral.

The needed parent/guardian consent that meets both Health Insurance Portability and Accountability Act (HIPAA) and Family Educational Rights and Privacy Act (FERPA) requirements are built into this form, which expedites effective information exchange. Not only does this consent authorize the referring agency to share information with Early Intervention, it also authorizes Early Intervention to share eligibility determination information back to the child’s medical home as well as the referring agency.

The Standardized Illinois Early Intervention Referral Form [pdf] can be found on HFS’ web site or refer to Appendix C of this toolkit.

A list of the 25 CFC offices in Illinois can be found at the DHS Office Locator or in Appendix D of this toolkit.

Using this form, the home visitor can identify:
- Information about the child
- Why the referral was made
- The referring party (in this case the home visitor)
- To whom the referral was made (which CFC)

Care Coordination Form (CCF) - Sharing Information with the Medical Home

It’s important to keep the medical home (including obstetricians and gynecologists, family practice physicians, and pediatricians) “in the loop” about any concerns you as a home visitor may have regarding the child, mother, and/or family’s well-being. The home visitor can offer the medical home a unique view into the family’s home life and
can be critical to the medical home’s ability to provide support and care. Issues such as maternal mental health (e.g., perinatal depression) might not be recognized during a routine well-child visit or ob-gyn exam, for example.

Likewise, it is important for the medical home to be able to share information about their patient with the home visitor. The home visitor has the ability to reinforce health care messaging.

The Illinois Chapter, American Academy of Pediatrics (ICAAP) has worked with home visitors, medical homes and MIECHV stakeholders to create a Care Coordination Form (CCF), to be used as a tool for communicating important information about the child, mother, and/or family with the medical home. The CCF can be used to inform the medical home that the child, mother, and/or family has been assigned a home visitor, and/or signal the medical home about concerns regarding the child’s development and/or concerns regarding the family’s home life. This form can also be used by home visitors to share information about the mom with her ob-gyn or primary care provider as concerns arise during pregnancy, and to share concerns about both the mom and child after pregnancy.

The needed parent/guardian consents that meet both the Health Insurance Portability and Accountability Act (HIPAA) and the Family Educational Rights and Privacy Act (FERPA) requirements are built into this form, expediting effective information exchange. This consent form authorizes the referring agency to share information with the medical home; it also provides consent for the medical home to share relevant patient information with the referring agency.

The Care Coordination Form [pdf] can be found at the ICAAP web site or in Appendix C of this toolkit. The Care Coordination Form Instructions for Use [pdf] document also can be found at the ICAAP web site or in Appendix C of this toolkit.

Using this form, the home visitor can:

- Identify information about the child and family
- Identify the reason for contacting the medical home
- Identify the referral source contact information (in this case, the home visitor)
- Request relevant patient medical information
Child Care Providers

Introduction

Child care providers often spend significant amounts of time with young children and have extensive opportunities to observe their behavior, patterns of social engagement (or the lack thereof), and routines such as feeding, sleeping etc. In addition, health and safety issues in out-of-home child care setting can range from simple to complex. Early education and child care professionals routinely handle certain health matters, such as responding to a minor injury or developing materials and procedures based on individual State Licensing and Regulation Information. However, when faced with more complex health concerns, such as a child’s potential developmental delay or “at risk” factors, care coordination in the form of information sharing with the child’s/family’s medical home could greatly benefit the child and her/his family.

ICAAP believes that:

- Connection with a child care provider gives the physician a view into the family’s home life and can be critical to his or her ability to provide care.
- The child care provider can share important information with the family to reinforce health care.

American Academy of Pediatrics (AAP) Policy Statements

The AAP, in its policy statement, Quality Early Education and Child Care From Birth to Kindergarten (January 2005, reaffirmed in 2009), states that high-quality early education and child care for young children improves their health and promotes their development and learning. Early education includes all of a child’s experiences at home, in childcare, and in other preschool settings. Physicians have a role in promoting access to quality early education and child care beginning at birth for all children.

The AAP policy statement, The Medical Home (July 2002, reaffirmed in 2008), recommends that comprehensive health care for infants, children, and adolescents should (also) include “interaction with early intervention programs, schools, early childhood education and child care programs, and other public and private community agencies to be certain that the special needs of the child and family are addressed.”

Referring to Early Intervention

A successful referral to Early Intervention requires the use of documentation such as the Standardized Illinois Early Intervention Referral Form to standardize the referral
process between the referring agency and the Child and Family Connections (CFC) office. A standardized form increases the accuracy and pace of the referral to Early Intervention, enhances communication among the medical home, the CFC, the home visitor and the family, and gauges the family’s experience and ability to follow-up on a referral.

The needed parent/guardian consent that meets both Health Insurance Portability and Accountability Act (HIPAA) and Family Educational Rights and Privacy Act (FERPA) requirements are built into this form, which expedites effective information exchange. Not only does this consent authorize the referring agency to share information with Early Intervention, it also authorizes Early Intervention to share eligibility determination information back to the child’s medical home as well as the referring agency.

The [Standardized Illinois Early Intervention Referral Form](pdf) can be found on HFS’ web site or refer to Appendix C of this toolkit.

A list of the 25 CFC offices in Illinois can be found at the DHS [Office Locator](#) or in Appendix D of this toolkit.

Using this form, the child care provider can identify:

- Information about the child
- Why the referral was made
- The referring party (in this case the child care provider)
- To whom the referral was made (which CFC)

**Care Coordination Form (CCF) - Sharing Information with the Medical Home**

It’s important to keep the medical home (including obstetricians and gynecologists, family practice physicians, and pediatricians) “in the loop” about any concerns you as a child care provider may have regarding the child, mother, and/or family’s well-being. The child care provider can offer the medical home a unique view into the family’s home life and can be critical to the medical home’s ability to provide support and care. Issues such as maternal mental health (e.g., perinatal depression) might not be recognized during a routine well-child visit or ob-gyn exam, for example.

The Illinois Chapter, American Academy of Pediatrics (ICAAP) has worked with home visitors and medical homes to create a [Care Coordination Form (CCF)](#), to be used as a tool for communicating important information about the child, mother, and/or family with the medical home. The CCF can be used to signal the medical home about concerns regarding the child’s development and/or concerns regarding the family’s home life. This form can also be used by child care providers to share information about the mom with her ob-gyn or primary care provider as concerns arise during pregnancy, and to share concerns about both the mom and child after pregnancy.
The needed parent/guardian consents that meet both the Health Insurance Portability and Accountability Act (HIPAA) and the Family Educational Rights and Privacy Act (FERPA) requirements are built into this form, expediting effective information exchange. This consent form authorizes the referring agency to share information with the medical home; it also provides consent for the medical home to share relevant patient information with the referring agency.

The Care Coordination Form [pdf] can be found at the ICAAP web site or in Appendix C of this toolkit. The Care Coordination Form Instructions for Use [pdf] document also can be found at the ICAAP web site or in Appendix C of this toolkit.

Using this form, the child care provider can identify:

- Information about the child and family
- The reason for contacting the medical home
- The referral source contact information (in this case, the child care provider)
Providers Serving Homeless Children and Families

Introduction

Homelessness has been found to be an independent predictor of poor health status and high service use among children. In one study, after controlling for potential explanatory factors, homeless children remained more likely to experience fair or poor health status. Homeless children have a higher incidence of trauma-related injuries, developmental delays, sinusitis, anemia, asthma, bowel dysfunction, eczema, and visual and neurologic deficits. Obesity and hunger are also common among homeless children. School-related problems are common among homeless children and include sporadic attendance or nonattendance, grade repetition, and below-average performance. Furthermore, runaway youth or young people living on the streets are at significant risk of violence and victimization, substance abuse, pregnancy, and sexually transmitted diseases, including HIV infection and AIDS.5

American Academy of Pediatrics (AAP) Policy Statements

In its statement Providing Care for Immigrant, Homeless, and Migrant Children, the AAP Committee on Community Health Services states that a substantial number of homeless children do not have a regular source of health care. Health becomes a lower priority as parents struggle to meet the family’s daily demands for food and shelter. Integration of health services with services provided by other agencies may improve access to care for children and adolescents who are living in shelters and do not have a medical home. Shelters and drop-in centers may act as gateways to other services and offer significant intervention potential for these families. Systems for tracking these children, such as portable medical records, need to be devised as a means of ensuring at least basic health care. Physicians who care for homeless patients must be cognizant of their patients' living environments and resource limitations. Special arrangements may be needed to address lack of transportation, child care, and communication (e.g., telephone) resources.

The AAP policy statement, *The Medical Home* (July 2002, reaffirmed in 2008), recommends that comprehensive health care for infants, children, and adolescents should (also) include “interaction with early intervention programs, schools, early childhood education and child care programs, and other public and private community agencies to be certain that the special needs of the child and family are addressed.”

**Executive Summary**

Children who experience homelessness are served by multiple systems: home visiting, child care, homeless shelters, WIC, as well as their medical home. Many of these systems offer not only family supports, but also preventive health services such as screening for perinatal maternal depression, vision, and developmental concerns. These services and referrals frequently are not coordinated among systems. Recognizing the challenges that vulnerable families face when navigating multiple social service systems and programs to meet their children’s needs, care coordination protocols can improve system capacity to meet the health, wellness, and developmental needs of families experiencing or at risk of experiencing homelessness by providing multi-system learning opportunities for health care providers, home visitors, community service providers, and others who serve these populations.

**Referring to Early Intervention**

A successful referral to Early Intervention requires the use of documentation such as the *Standardized Illinois Early Intervention Referral Form* to standardize the referral process between the referring agency and the Child and Family Connections (CFC) office. A standardized form increases the accuracy and pace of the referral to Early Intervention, enhances communication among the medical home, the CFC, and providers serving homeless children and families, and gauges the family’s experience and ability to follow-up on a referral.

The needed parent/guardian consent that meets both Health Insurance Portability and Accountability Act (HIPAA) and Family Educational Rights and Privacy Act (FERPA) requirements are built into this form, which expedites effective information exchange. Not only does this consent authorize the referring agency to share information with Early Intervention, it also authorizes Early Intervention to share eligibility determination information back to the child’s medical home as well as the referring agency.

The *Standardized Illinois Early Intervention Referral Form* [pdf] can be found on HFS’ web site or refer to Appendix C of this toolkit.

A list of the 25 CFC offices in Illinois can be found at the DHS Office Locator or in Appendix D of this toolkit.
Using this form, providers serving homeless children and families can identify:

- Information about the child
- Why the referral was made
- The referring party (in this case those serving the homeless child and family)
- To whom the referral was made (which CFC)

**Care Coordination Form - Sharing Information with the Medical Home**

It’s important to keep the medical home “in the loop” about any concerns you as a provider may have about the child or family. Providers serving homeless children and families can offer the medical home a unique view into the family and child’s daily life and can be critical to his or her ability to provide care. Likewise, it is important for the medical home to be able to share information about their patient with the providers serving homeless children and families. Finally, this provider has the ability to reinforce health care messaging.

ICAAP has worked with home visitors and medical homes to create a Care Coordination Form, to be used as a tool for communicating important information about the child and/or family with the medical home. This form can be used to let the medical home know that the child and/or family has been assigned a caseworker, and/or alert the medical home to concerns regarding the child’s development.

The needed parent/guardian consent that meets both Health Insurance Portability and Accountability Act (HIPAA) and Family Educational Rights and Privacy Act (FERPA) requirements are built into this form, which expedites effective information exchange. Not only does this consent authorize the referring agency to share information with the medical home, it also provides consent for the medical home to share patient information with the referring agency.

The Care Coordination Form [pdf] can be found at the ICAAP web site or in Appendix C of this toolkit. The Care Coordination Form Instructions for Use [pdf] document also can be found at the ICAAP web site or in Appendix C of this toolkit.

Using this form, the provider serving homeless children and families can:

- Identify information about the child and family
- Identify the reason for contacting the medical home
- Identify the referral source contact information
- Request relevant patient medical information
APPENDIX A: GLOSSARY OF TERMS

Recognizing that different providers and systems use a variety of words to describe how they connect families to appropriate developmental and community resources, we have briefly defined common terms.

<table>
<thead>
<tr>
<th><strong>Agency</strong></th>
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<tbody>
<tr>
<td>An organization that offers programs and services for families and their children</td>
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</table>

<table>
<thead>
<tr>
<th><strong>Assessment</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>An assessment is the evaluation or estimation of the nature, quality, or ability of someone or something. More specifically, an assessment is “the process of exploring the meaning of information that emerges from screening and understanding its implications for decisions that the connecting service and a provider might make. Assessments, often structures as a follow-up conversation to initial screening, have to be multi-faceted and ongoing in order to capture those complexities of a family’s experiences that might be most important to a successful referral.”</td>
</tr>
</tbody>
</table>

**NOTE**: Part C federal guidelines are very specific about defining “assessment” as it relates to Early Intervention:

**Determining Strengths and Needs of the Child and the Family (Assessment)**

§303.321(a)(2)

(ii) Assessment means "the 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 assessment of the child's family..."

(iii) Initial assessment refers to "the assessment of the child and the family assessment conducted prior to the child's first IFSP meeting."

§303.321(c)

"Procedures for assessment of the child and family. (1) An assessment of each infant or toddler with a disability must be conducted by qualified personnel in order to identify the child's unique strengths and needs and the early intervention services appropriate to meet those needs. The assessment of the child must include the following—

(i) A review of the results of the evaluation conducted under paragraph (b) of this section;

(ii) Personal observations of the child; and

(iii) The identification of the child's needs in each of the developmental areas in §303.21(a)(1)."

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6 ABCD III Compendium
At risk of substantial developmental delay, according to informed clinical judgment
The multidisciplinary team confirms that development of a Department determined eligible level of delay (30% or greater) is probable if Early Intervention services are not provided because the child is experiencing either:

- A parent who has been medically diagnosed as having a severe mental disorder as set forth under axis I and axis II of the Diagnostic and Statistical Manual (DSM) IV or a developmental disability; or
- Three or more of the following risk factors:
  - Current alcohol or substance abuse by the primary caregiver;
  - Primary caregiver who is currently less than 15 years of age;
  - Current homelessness of the child. Homelessness is defined as children who lack a fixed, regular and adequate nighttime residence, in conformity with the McKinney Vento Homeless Assistance Act;
  - Chronic illness of the primary caregiver;
  - Alcohol or substance abuse by the mother during pregnancy with the child;
  - Primary caregiver with a level of education equal to or less than the 10th grade, unless that level is appropriate to the primary caregiver’s age;
  - An indicated case of abuse or neglect regarding the child and the child has not been removed from the abuse or neglect circumstances.

Care Coordination
A client-centered, assessment-based interdisciplinary approach to integrating health care and social support services in which an individual’s needs and preferences are assessed, a comprehensive care plan is developed, and services are managed and monitored by an identified care coordinator following evidence based standards of care.7

7 National Coalition on Care Coordination (N3C)
Care Coordination Form (CCF)

The CCF is to be used by community service providers (e.g. home visitors, child care providers, and providers of services to homeless children and families) as a tool for communicating important information about the child, mother, and/or family with the medical home. The CCF can be used to inform the medical home that the child, mother, and/or family has been assigned a service provider, and/or signal the medical home about concerns regarding the child’s development and/or concerns regarding the family’s home life. This form can also be used by service providers to share information about the mom with her ob-gyn or primary care provider as concerns arise during pregnancy, and to share concerns about both the mom and child after pregnancy.

The needed parent/guardian consents that meet both the Health Insurance Portability and Accountability Act (HIPAA) and the Family Educational Rights and Privacy Act (FERPA) requirements are built into this form, expediting effective information exchange. This consent form authorizes the referring agency to share information with the medical home; it also provides consent for the medical home to share relevant patient information with the referring agency.

Case Management

Case Management can have multiple definitions across a variety of settings, depending on the provider and the patient. For the purposes of this toolkit, case management is defined as “a collaborative practice model including patients, nurses, social workers, physicians, other practitioners, caregivers and the community. The case management process encompasses communication and facilitates care along a continuum through effective resource coordination. The goals of case management include the achievement of optimal health, access to care and appropriate utilization of resources, balanced with the patient’s right to self-determination.”8 By implementing a referral and follow-up method as suggested in this toolkit, providers will be able to engage in improved case management with their target populations.

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8 American Case Management Association (ACMA)
**Child and Family Connections (CFC)**
Child and Family Connections is the starting point for the referral of all children less than 36 months of age to the Part C Early Intervention Service in Illinois. Each CFC is staffed with the following personnel:
- Program Manager
- Service Coordinator
- Parent Liaison
- Social Emotional Coordinator

These staff members are responsible for ensuring that:
- All of the opportunities under the Part C Early Intervention Services System are made available to families
- Families are provided accurate and timely information about their options
- Families receive thorough information regarding their rights under federal and state law.

**Community**
A specific group of people living in the same locality who may share a common culture, values, and norms.

**Community Service Provider (CSP)**
A community service provider is offering a service within the community, usually performed in connection with a nonprofit organization, funded by grants or governmental agencies, one or more businesses, or by individuals.

**Coordinated Intake Office**
Coordinated Intake offices serve as the hub for intake for new families. There are several different models for coordinated intake. In most cases, coordinated intake workers conduct outreach to families and complete the Coordinated Intake Assessment Tool (CIAT), which collects program eligibility information before referring families to an appropriate home visiting program.
Developmental Delay

"Developmental delay" means the Illinois Department of Human Services (Department) determined eligible level of delay (30% or greater) in one or more of the following areas of childhood development: cognitive; physical, including vision and hearing; language, speech and communication; social-emotional; or adaptive self-help skills. The eligible level of delay must have been:

- Measured by Department approved diagnostic instruments and standard procedures (see the following Assessment Instruments list); or
- Confirmed through informed clinical judgment of the multidisciplinary team if the child is unable to be appropriately and accurately tested by the standardized measures available. Activities used to determine clinical judgment shall include observation and parent report and shall be described in the written evaluation report.

Early Head Start (EHS) Home-Based Model

EHS Home-Based Model provides high-quality, culturally competent child development and parent support services with an emphasis on the role of the parent as the child's first, and most important relationship.

Target Population
Low-income pregnant women and families of infants and toddlers.

Program Purpose
EHS is a comprehensive, two-generation initiative aimed at enhancing the development of infants and toddlers while strengthening families.

Key Services
- Developmental screening, ongoing observation and assessment, and curriculum planning
- Medical, dental, and mental health
- Child development and education
- Family partnerships and goal setting
- Community collaborations to meet additional family needs

Early Intervention

Early Intervention is a system of coordinated services that promotes the child's growth and development and supports families during the critical early years. Early Intervention services to eligible children and families are federally mandated through the Individuals with Disabilities Education Act (IDEA). Starting with a partnership between parents and professionals at this early stage helps the child, family and community as a whole.
Eligibility for Early Intervention
Children residing in Illinois who are under the age of three years and their families are initially eligible for Early Intervention services if written evaluation reports completed by a multidisciplinary team confirm that the child:

- Has a developmental delay; or
- Has a physical or mental condition which typically results in developmental delay; or
- Is at risk of having substantial developmental delays, according to informed clinical opinion.

FERPA: Family Educational Rights and Privacy Act
The Family Educational Rights and Privacy Act (FERPA) (20 U.S.C. § 1232g; 34 CFR Part 99) is a Federal law that protects the privacy of student education records. The law applies to all schools that receive funds under an applicable program of the U.S. Department of Education.

FERPA gives parents certain rights with respect to their children's education records. These rights transfer to the student when he or she reaches the age of 18 or attends a school beyond the high school level. Students to whom the rights have transferred are "eligible students."

- Parents or eligible students have the right to inspect and review the student's education records maintained by the school. Schools are not required to provide copies of records unless, for reasons such as great distance, it is impossible for parents or eligible students to review the records. Schools may charge a fee for copies.
- Parents or eligible students have the right to request that a school correct records which they believe to be inaccurate or misleading. If the school decides not to amend the record, the parent or eligible student then has the right to a formal hearing. After the hearing, if the school still decides not to amend the record, the parent or eligible student has the right to place a statement with the record setting forth his or her view about the contested information.
- Generally, schools must have written permission from the parent or eligible student in order to release any information from a student's education record. However, FERPA allows schools to disclose those records, without consent, to the following parties or under the following conditions (34 CFR § 99.31):
  - School officials with legitimate educational interest;
  - Other schools to which a student is transferring;
  - Specified officials for audit or evaluation purposes;
  - Appropriate parties in connection with financial aid to a student;
  - Organizations conducting certain studies for or on behalf of the school;
  - Accrediting organizations;
  - To comply with a judicial order or lawfully issued subpoena;
  - Appropriate officials in cases of health and safety emergencies; and
  - State and local authorities, within a juvenile justice system, pursuant to
Healthy Families Illinois (HFI)

HFI is a voluntary, intensive home visiting program that reduces family isolation, supports parents as children's first teachers and caretakers, and helps parents develop good parenting skills.

**Target Population**
Families who are at risk of child abuse and neglect. HFI provides voluntary, culturally relevant services to both fathers and mothers.

**Program Purpose**
Promote healthy child development and reduce child abuse and neglect among at risk families

**Key Services**
- Teaching and modeling effective parenting skills
- Providing social support for new parents to reduce social isolation
- Connecting parents to other services in the community
- Removing barriers to services such as lack of transportation or child care
- Monitoring and promoting children’s development
- Supporting parent child attachment
HIPAA: Health Insurance Portability and Accountability Act
The HIPAA Privacy Rule provides federal protections for personal health information held by covered entities and gives patients an array of rights with respect to that information. At the same time, the Privacy Rule is balanced so that it permits the disclosure of personal health information needed for patient care and other important purposes.

The Security Rule specifies a series of administrative, physical, and technical safeguards for covered entities to use to assure the confidentiality, integrity, and availability of electronic protected health information.

Homeless
The National Center for Homeless Education at SERVE Best Practices in Homeless Education Brief Series states the McKinney-Vento Homeless Assistance Act reauthorized in 2001 by Title X, Part C of the No Child Left Behind Act – Sec 725) as:

“The term ‘homeless children and youth’ —
A. means individuals who lack a fixed, regular, and adequate nighttime residence…;
and
B. includes —
  i. children and youths who are sharing the housing of other persons due to loss of housing, economic hardship, or similar reason; are living in motels, hotels, trailer parks, or camping grounds due to the lack of alternative accommodations; are living in emergency or transitional shelters; are abandoned in hospitals; or are awaiting foster care placement;
  ii. children and youths who have a primary nighttime residence that is a public or private place not designed for or ordinarily used as a regular sleeping accommodation for human beings…
  iii. children and youths who are living in cars, parks, public spaces, abandoned buildings, substandard housing, bus or train stations, or similar settings; and
  iv. migratory children who qualify as homeless for the purposes of this subtitle because the children are living in circumstances described in clauses (i) through (iii).

Home Visiting
Programs that includes home visiting as a primary service delivery strategy (excluding programs with infrequent or supplemental home visiting), and is offered on a voluntary basis to pregnant women or children birth to age 5 targeting one or more of the participant outcomes in the legislation including improved maternal and child health, prevention of child injuries, child abuse, or maltreatment, and reduction of emergency department visits, improvement in school readiness and achievement, reduction in crime or domestic violence, improvements in family economic self-sufficiency, and
improvements in the coordination and referrals for other community resources and supports.

**Home Visiting Providers**
Nurses, social workers, or other trained home visitors meet with at risk families in their homes, evaluate the families’ circumstances, and connect families to the type of assistance that can make a real difference in a child’s health, development, and ability to learn—such as health care, developmental services for children, early education, parenting skills, child abuse prevention, and nutrition education or assistance.

**Individuals with Disabilities Education Act (IDEA)**
The Individuals with Disabilities Education Act (IDEA) is a law ensuring services to children with disabilities throughout the nation. IDEA governs how states and public agencies provide early intervention, special education and related services to more than 6.5 million eligible infants, toddlers, children and youth with disabilities.
- **IDEA Part B:** Children and youth (ages 3-21) receive special education and related services under IDEA Part B.
- **IDEA Part C:** Infants and toddlers with disabilities (birth-2) and their families receive early intervention services under IDEA Part C.

**Illinois Chapter, American Academy of Pediatrics (ICAAP)**
The Illinois Chapter of the American Academy of Pediatrics (ICAAP) is an organization of approximately 2,300 pediatricians in Illinois. Primary activities include advocacy on behalf of children, families, and health professionals in Illinois; the provision of continuing medical education and other resources for pediatricians, pediatric specialists, and other child health care providers; and collaboration with other state organizations and agencies on programs and projects that improve the health and well-being of children.

ICAAP’s mission is to promote the right of all children to live happy, safe, and healthy lives, to ensure children receive quality medical care from pediatricians (the most qualified physicians to deliver this care), and to assess and serve the needs of its membership.
Illinois Department of Healthcare and Family Services (HFS)
The Illinois Department of Healthcare and Family Services (HFS) provides healthcare coverage for adults and children who qualify for Medicaid, and for providing child support services to help ensure that Illinois children receive financial support from both parents. The agency is organized into two major divisions, Medical Programs and Child Support Services. In addition, the Office of Inspector General is maintained within the agency, but functions as a separate, independent entity reporting directly to the governor's office.

Illinois Department of Human Services (DHS)
The Illinois Department of Human Services (DHS) offers a comprehensive and coordinated array of social services to help improve the quality of life for thousands of individuals, families and communities across the state. DHS administers community health and prevention programs, oversees interactive provider networks that treat persons with developmental disabilities, mental health and substance abuse challenges and provides rehabilitation services. DHS also aids eligible, low-income individuals and families with essential financial support, locating training and employment opportunities and obtaining child care in addition to other family services.

Intake
The family’s entry point for services at which eligibility is assessed against established criteria and a preliminary screening of the presenting problem occurs.
Maternal, Infant and Early Childhood Home Visiting (MIECHV) Program

Authorized by the Patient Protection and Affordable Care Act that was signed on March 23, 2010, the Maternal, Infant and Early Childhood Home Visiting (MIECHV) Program was established through a federal grant process issued jointly by Health Resources and Services Administration (HRSA), and the Administration for Children and Families (ACF). The purpose of the Program is to respond to the diverse needs of children and families and provide an opportunity for collaboration and partnership at the federal, state and community levels to improve health and developmental outcomes for at risk children through evidence based home visiting programs.

MIECHV is designed to use evidence based home visitation as a strategy to:

1. Strengthen and improve the programs and activities carried out under the Title V Maternal and Child Health Program
2. Improve coordination of services for at risk communities
3. Identify and provide comprehensive services to improve outcomes for families who reside in at risk communities.

Targeted participant outcomes include:
- Improved maternal and child health
- Prevention of child injuries, child maltreatment, and reduction of emergency department visits
- Improvement in school readiness and achievement
- Reduction in crime or domestic violence
- Improvements in family economic self-sufficiency
- Improvements in the coordination and referrals for other community resources and supports

The evidence based Home Visiting program models used in Illinois are:
- **Early Head Start, Home Based (EHSHB)**
  Serving low-income pregnant women and families with children from birth to age 3.
- **Healthy Families America (HFA)**
  Serving at risk families with children from birth to age 5.
- **Nurse-Family Partnerships (NFP)**
  Serving first time low-income mothers from pregnancy until the baby turns two years old.
- **Parents as Teachers (PAT)**
  Serving families with children from birth to age 5.
Medical Home
The medical home, also known as the Patient-Centered Medical Home (PCMH), is a team based health care delivery model led by a physician that provides comprehensive and continuous medical care to patients with the goal of obtaining maximized health outcomes. The PCMH facilitates partnerships between individual patients and their personal physicians, and when appropriate, the patient’s family. Care is facilitated by registries, information technology, health information exchange and other means to assure that patients get the indicated care when and where they need and want it in a culturally and linguistically appropriate manner.

Medical Home Referral Form to MIECHV Coordinated Intake Office
This form can be used by medical homes to initiate the process to determine patient/family eligibility for home visiting services. The form can be faxed to the appropriate Coordinated Intake office in one of the six MIECHV communities. The Coordinated Intake office shares the referral outcome with the medical home using the Coordinated Intake Office Referral Fax Back Form.

MIECHV Communities
The six communities associated with the Maternal, Infant and Early Childhood Home Visiting (MIECHV) program are:
1. Englewood, West Englewood, Greater Grand Crossing
2. Cicero Township
3. City of Elgin
4. City of Rockford
5. Macon County
6. Vermilion County
**MIECHV Coordinated Intake Office Referral Fax Back Form**

This form is to be used by the Coordinated Intake office to inform the primary care provider about referral outcome (based on medical home referral, using the Medical Home Referral Form to MIECHV Coordinated Intake Office), i.e., eligibility for home visiting services and/or other referrals received.

**NOTE:** Information can be released to the primary care provider identified under Section 5. Authorization to Release Information, clause b. of the Medical Home Referral Form to MIECHV Coordinated Intake Office. The patient or parent/guardian (if the patient is under 18) must sign a separate consent form in order to send the information shown below to an entity other than the referral source listed under Section 5. Authorization to Release Information, clause b. of the Medical Home Referral Form to MIECHV Coordinated Intake Office.

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**MIECHV Home Visiting Providers**

MIECHV Home visitors are professionals or paraprofessionals who have received background checks and have experience related to child development and family strengthening. They have also received extensive training in their agency’s home visiting model as well as core knowledge and skills relating to domestic violence, substance abuse, developmental disabilities, and maternal depression. MIECHV home visitors, in the course of their work with families, complete the following screenings and refer families for services as indicated:

- 4P’s Plus (substance abuse screening)
- Relationship Assessment Tool (domestic violence screening)
- Edinburg Assessment (maternal depression)
- ASQ-3 Assessment (child cognitive development)
- ASQ-SE Assessment (child socio-emotional development)
Nurse-Family Partnership (NFP)
NFP is an evidence based community health program that helps transform the lives of vulnerable mothers pregnant with their first child. Each mother served by NFP is partnered with a registered nurse early in her pregnancy and receives ongoing nurse home visits that continue through her child’s second birthday.

Target Population
First time, low income mothers.

Program Purpose
- Improve pregnancy outcomes of mother
- Improve child health and development outcomes
- Improve parental economic self sufficiency

Key Services
Client centered, strength-based, culturally competent services are delivered to the mothers and families. Services include personal health, environmental health, life course development, maternal role, relational work, health and human services.

Parents As Teachers (PAT)
PAT is a home-based family education and support program. Through this program, parents acquire skills that help them make the best of children’s crucial early learning years.

Target Population
Parents with children from the prenatal stage through age 5.

Program Purpose
To provide the information, support, and encouragement parents need to help their children develop optimally during the crucial early years of life.

Key Services
- Developmental screening, ongoing observation and assessment
- Prevention of child abuse and neglect
- Child development and education
- Family partnerships and goal setting
- Community collaborations to meet additional family needs
Physical or mental condition which typically results in developmental delay

A medical diagnosis:
1. Approved by the Illinois Department of Human Services as an eligible condition; (see the following list of Medical Conditions Resulting in a High Probability of Developmental Delay); or
2. Confirmed by a qualified family physician, pediatrician or pediatric sub-specialist as being a condition with a relatively well known expectancy for developmental outcomes within varying ranges of developmental disabilities. Pediatric subspecialists included are those such as pediatric neurologists, geneticists, pediatric orthopedic surgeons and pediatricians with special interest in disabilities. If a child exhibits a medical condition not approved by the Illinois Department of Human Services as being an eligible condition, the qualified multidisciplinary team may use written verification by one of the physician categories identified above that the child's medical condition typically results in substantial developmental delay within the varying ranges of developmental disabilities.

Program

A system of services offered by an organization is called a program. For example, an organization providing a mental health service may offer several mental health programs to different populations, e.g., a mental health program for adolescent teens.

Provider

A provider is a physician, advance practice nurse or physician assistant, chosen by or assigned to a patient, who both provides primary care and acts as a gatekeeper to other medical services.

Referral

A process of providing information about services, program eligibility, and the availability of those services, and the routing or selecting of children and their families for particular service delivery or program participation.
Referral Form (standardized)
Standardized form used by an agency (medical home, child care provider, home visitor) when making a referral to an Early Intervention agency. A successful referral requires use of documentation such as the Illinois Standardized Early Intervention Referral Form to standardize the referral process between the referring agency and the Child and Family Connections (CFC) office. A standardized form increases the accuracy and pace of child referral to Early Intervention, enhances communication among the medical home, the CFC, and the family, and gauges the family’s experience and ability to follow-up on referral.

REMEMBER: In order to expedite effective information exchange needed parent/guardian consent that meets both Health Insurance Portability and Accountability Act (HIPAA) and Family Educational Rights and Privacy Act (FERPA) requirements is also built into this form.

Resource
A resource is a program or agency that will provide families with services, information and support related to child development.

Risk Assessment
A risk assessment tool assists the health care provider in objectively identifying the factors that predispose an individual to make decision(s) leading to risk taking behavior, as well as take preventive action by addressing the situation promptly either by treatment or referral to an appropriate agency for support and services. Administration of an approved risk assessment instrument is essential in early identification of physical and mental problems in all age groups.9

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9 January 2015 Handbook for Providers of Healthy Kids Services Chapter HK-200 – Policy and Procedures
Screening
Screening is “the initial evaluation of an individual, intended to determine suitability for a particular treatment modality.”\textsuperscript{10} In the early childhood field, many providers equate screenings with developmental screenings.

The U.S. Centers for Disease Control and Prevention (CDC) defines developmental screenings as a short test to tell if children are learning basic skills when they should, or if they might have delays. For this toolkit we are focusing on developmental screenings to identify the needs of an individual child within the context of their family and environment.

Screening Tools
Questionnaires used by health care professionals to assist with diagnosis.

Service
A service is one or more organization operated activities that have a common general objective and deploy the organization's resources in a planned and systematic manner. In the context of this document, a service refers to activities that enable individuals, families, and groups to cope with or overcome developmental, social and psychological problems interfering with their child's learning and development.

Statewide Provider Database (SPD)
The Illinois Department of Children and Family Services (DCFS) Statewide Provider Database (SPD) [pdf] is an online database with comprehensive information on service agencies and programs throughout Illinois. The SPD was developed to assist caseworkers in identifying and locating appropriate services for their clients. SPD contains information on services that are open to all children and families. SPD saves you time by searching all the available resources for the closest provider that offers the service you are looking for. Each program location in the SPD is assigned a geocode which allows SPD users to search for services by distance from a client's location. The SPD is located at the DCFS Welcome to the Illinois Outcomes web site. DCFS employees can contact the DCFS helpdesk at 800-610-2089 to get access to the SPD. Non-DCFS employees can contact Erik Sandberg at Erik.Sandberg@illinois.gov get access to the SPD.

\textsuperscript{10}The American Heritage Medical Dictionary Copyright 2007, 2004 by Houghton Mifflin Company. Published by Houghton Mifflin Company
## APPENDIX B: FAQ

<table>
<thead>
<tr>
<th>Q: Why should my practice change the procedure for referrals? We already have one and it is working fine.</th>
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</thead>
<tbody>
<tr>
<td>A: If your practice has an effective procedure for making, tracking, follow up, and documentation of referrals to Early Intervention, special education (SPED), and/or prevention programs, that allow for ease of access to status of referral and information sharing, you do not need to change. CONGRATULATIONS.</td>
</tr>
<tr>
<td>HOWEVER: Consider using the Standardized Illinois Early Intervention Referral Form to enhance the relationship with Early Intervention and to ensure that you get INFORMATION BACK from Early Intervention about the referral.</td>
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<table>
<thead>
<tr>
<th>Q: Is it really necessary to use the Standardized Illinois Early Intervention Referral Form?</th>
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<tr>
<td>A: While it is not necessary to use this particular form, both Early Intervention staff and many of your colleagues are being trained to use it because of the features built into the form. A successful referral to Early Intervention requires the use of documentation such as the Standardized Illinois Early Intervention Referral Form to standardize the referral process between the referring agency and the Child and Family Connections (CFC) office. A standardized form increases the accuracy and pace of the referral to Early Intervention, enhances communication among the medical home, the CFC, the referring agency and the family, and gauges the family’s experience and ability to follow-up on a referral.</td>
</tr>
<tr>
<td>The needed parent/guardian consent that meets both Health Insurance Portability and Accountability Act (HIPAA) and Family Educational Rights and Privacy Act (FERPA) requirements are built into this form, which expedites effective information exchange. Not only does this consent authorize the referring agency to share information with Early Intervention, it also authorizes Early Intervention to share eligibility determination information back to the child’s medical home as well as the referring agency.</td>
</tr>
<tr>
<td>The Standardized Illinois Early Intervention Referral Form [pdf] can be found on HFS’ web site or in Appendix C of this toolkit. A list of the 25 CFC offices in Illinois can be found at the DHS Office Locator or in Appendix D of this toolkit.</td>
</tr>
</tbody>
</table>
Q: Can I screen my patients at only the 18-month mark? I haven’t done 9 and 12 month olds in the past.

A: Yes, developmental screening at 18 months is appropriate. The American Academy of Pediatrics (AAP) recommends earlier developmental screenings using a validated screening tool because it has been demonstrated that earlier screening provides a baseline for comparison and is effective in making decisions about the need for additional interventions for developmental concerns.

Q: I use the Denver Screening tool. Do I need to change?

A: With publication of the revision to the Handbook for Providers of Healthy Kids Services, January 2015, the Denver will not be permitted for reimbursement after December 2015. As a medical home, it is important to remain current on most effective tools available for any aspect of your work and as such, you will want to review the use of each tool.

Q: Can only the MD complete the Standardized Illinois Early Intervention Referral Form?

A: No, the Standardized Illinois Early Intervention Referral Form can be completed and faxed to the appropriate CFC by any medical paraprofessional, community service provider, or child care provider agency. This includes but is not limited to MDs, RNs, Home Visiting Staff, Child Care Workers and providers of services to homeless children and families.

Q: If I have already screened the child for developmental delays at 9 months, do I need to rescreen at 12 and 18 months?

A: The AAP recommends routine developmental screening at additional intervals because some developmental concerns might not be apparent at 9 months. For additional information about AAP recommendations for developmental screening, please see the AAP Policy statement Identifying Infants and Young Children With Developmental Disorders in the Medical Home: An Algorithm for Developmental Surveillance and Screening.
**Q: Why should the medical home make the 36-hour follow-up call?**

**A:** One of the lessons learned from previous care coordination work is that families will almost immediately talk with other family members, close friends, and those who offer support such as clergy about “what the doctor said”. They will have made a decision about whether to follow up on the referral within a very short period of time after these conversations. Medical homes can have influence and additional input into the family’s decision making in a non-threatening and non-authoritarian way by making the 36 hour follow up call. Within 36 hours of making referral, if designated practice staff makes a follow up phone call to families of the above identified children the medical home or home visitor or other referring entity has the opportunity to offer encouragement and support and confirm and document family’s intent to use the referral.

**Q: If my families are not eligible for Early Intervention services, can I use the Statewide Provider Database (SPD) to refer them to other resources in the community?**

**A:** Yes, you can use the SPD even if the child is eligible for Early Intervention. Early Intervention is not equipped to address all of the needs that a family might have. The SPD allows access to a wide range of Illinois community programs and resources such as Mental Health, Domestic Violence, and Substance Abuse programs. The SPD is located at the DCFS Welcome to the Illinois Outcomes web site. DCFS employees can contact the DCFS helpdesk at 800-610-2089 to get access to the SPD. Non-DCFS employees can contact Erik Sandberg at Erik.Sandberg@illinois.gov get access to the SPD.

**Q: There are other doctors in my practice who do not need to fulfill MOC requirements. Should I have them follow the screening guidelines and use the referral forms as well?**

**A:** MOC is about practice change and therefore it is useful to encourage all team members to participate in the MOC requirements.

**Q: If the family I have referred to Early Intervention has not heard from the CFC, can my office make a call to check the status of the referral?**

**A:** Yes. Because the CFCs receive referrals by fax, the referral might not have been properly transmitted, received, or even sent to the correct CFC location.
Q: Can my practice make changes to the Standardized Illinois Early Intervention Referral Form?

A: The authors do not encourage changes to the consent section of the form as it has already been vetted for HIPAA and FERPA information exchange. However, the changes that medical homes or other organizations sometimes make to this form include adding the practice name, address, phone number, and CFC list to be checked. If you would like to receive a WORD version of this form for editing, please contact Elise Groenewegen at EGroenewegen@illinoisaap.com

Q: Can my organization make changes to the Care Coordination Form?

A: The authors do not encourage changes to the consent section of the form as it has already been vetted for HIPAA and FERPA information exchange. However, the changes that organizations sometimes make to this form include adding the organization name, address, and phone number. If you would like to receive a WORD version of this form for editing, please contact Elise Groenewegen at EGroenewegen@illinoisaap.com

Q: How do you determine which Early Intervention location is appropriate for the family?

A: The CFC offices are the entry point into the Early Intervention program in Illinois. A list of the 25 CFC offices in Illinois can be found at the DHS Office Locator or in Appendix D of this toolkit. Which CFC office to refer to is determined by the family’s residential county or zip code (if the family resides in Cook County).

Q: How do you determine which MIECHV Coordinated Intake office location is appropriate for the family?

A: The MIECHV Coordinated Intake offices serve as the hub for intake for new families. There are several different models for coordinated intake: in most cases, coordinated intake workers conduct outreach to families and complete the Coordinated Intake Assessment Tool (CIAT), which collects program eligibility information before referring families to an appropriate home visiting program. There is one Coordinated Intake Office in each of the six MIECHV communities. Each office and fax number is listed on the Medical Home Referral Form to MIECHV Coordinated Intake Office [pdf].
Q: What happens after the Coordinated Intake office receives a referral?

A: After receiving the Medical Home Referral Form to Coordinated Intake Office, the Coordinated Intake Worker (CIW):

- Contacts the family referred by the medical home
- Completes the Coordinated Intake Assessment Tool (CIAT) over the phone or in person
- Refers 100% of positive screens to the most appropriate (for the client) home visiting provider within 24 hours
- If all home visiting providers are at capacity, refers to appropriate community resources and places client on waiting list for home visiting services. (Waiting list clients will receive a minimum of a monthly contact to monitor availability of services and eligibility of client.)
- Provides immediate referrals to community resources for 100% of clients presenting with emergency needs
- Refers 100% of negative screens to other community and parenting services as indicated
- Notifies the client’s medical home of their eligibility for home visiting services and/or other referrals received using the Coordinated Intake Office Referral Fax Back Form

**REMEMBER:** Referral Outcome information can be released to the primary care provider identified under Section 5. Authorization to Release Information, clause b. of the Medical Home Referral Form to MIECHV Coordinated Intake Office. The patient or parent/guardian (if the patient is under 18) must sign a separate consent form in order to send the information shown below to an entity other than the referral source listed under Section 5. Authorization to Release Information, clause b. of the Medical Home Referral Form to MIECHV Coordinated Intake Office.
Q: What happens after a patient/family is enrolled in a home visiting program?

A: Once the patient/family is enrolled by the assigned home visiting program:

- The home visitor completes all case management, including regular screenings, assessments and observations.
- In the course of working with the family, the home visitor completes the following screening:
  - 4P’s Plus (substance abuse screening)
  - Relationship Assessment Tool (domestic violence screening)
  - Edinburgh Assessment (maternal depression)
  - ASQ-3 Assessment (child cognitive development)
  - ASQ-SE Assessment (child socio-emotional development)
- The home visitor refers to appropriate services as indicated by screening results.

In the course of working with the family, the home visitor shares pertinent information regarding the client/patient/family with the medical home using the Care Coordination Form (CCF).

Q: What is the timeline for referral to Early Intervention?

A: According to federal law, once a developmental concern is identified by a care provider, the patient has the right to be referred to the appropriate CFC within five days. Once the patient is referred, the CFC must evaluate and assess the patient and determine his or her eligibility for specific programs and services.

If the child is determined eligible for Early Intervention services, Early Intervention must then work with the families of the eligible child to formulate a service plan within 45 calendar days after the referral has been received. This is called an Individual Family Service Plan (IFSP). This plan is reviewed for progress every year with opportunities for additional review sooner as needed.
Q: What happens after the CFC receives a referral?

A: Once the CFC receives the Standardized Illinois Early Intervention Referral Form, the CFC service managers will assign the family to a CFC service coordinator. CFC coordinators assist families in obtaining screenings and evaluations to determine eligibility for the Early Intervention program, assess service needs of eligible children, plan for needed services, and choose credentialed providers.

The CFC is encouraged to share information about the referral with the referring medical home using the Illinois Early Intervention Referral Fax Back Form [pdf]. This form will let the medical home know if:

- The CFC was able to establish contact with the family
- A Service Coordinator has been assigned to the family
- The family has declined services
- The child has been evaluated and found to be not eligible for services
- The child has been evaluated and found to be eligible for services
- The child and family have been recommended to receive Early Intervention services (and will indicate what type)
- An IFSP was/will be developed for the child and family
- The child and family received referrals to non-Early Intervention services

**REMEMBER:** Section 6 of the Standardized Illinois Early Intervention Referral Form authorizes the CFC to release information back to the primary care provider and/or referring agency in compliance with HIPAA and FERPA requirements.
APPENDIX C: FORMS FOR CARE COORDINATION PROTOCOL

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<tr>
<td>• Communication with Families About Making a Referral to Early Intervention [pdf]</td>
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<tr>
<td>• Providing the Family with Helpful Guidance after a Referral Has Been Made [pdf]</td>
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<td>• MIECHV Coordinated Intake Office Referral Fax Back Form [pdf]</td>
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<th>Home Visitors</th>
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<td>• Care Coordination Form Instructions for Use [pdf]</td>
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### Messaging Tools
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- Communication with Families About Making a Referral to Early Intervention [pdf]
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### Medical Home
- Standardized Illinois Early Intervention Referral Form [pdf]
- Illinois Early Intervention Program Referral Fax Back Form [pdf]
- Example of Medical Home Team Responsibility [pdf]
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- Medical Home Referral Form to Coordinated Intake Office [pdf]
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### Providers Serving Homeless Children and Families
- Care Coordination Form [pdf]
- Standardized Illinois Early Intervention Referral Form [pdf]
Messaging Tools

- Communication with Families When Screening for Developmental Concerns [pdf]
- Communication with Families About Making a Referral to Early Intervention [pdf]
- Providing the Family with Helpful Guidance after a Referral Has Been Made [pdf]
# APPENDIX D: HELPFUL RESOURCES

## American Academy of Pediatrics (AAP) Policy Statements

- Care Coordination in the Medical Home: Integrating Health and Related Systems of Care for Children With Special Health Care Needs
- Identification and Evaluation of Children With Autism Spectrum Disorders
- Identifying Infants and Young Children With Developmental Disorders in the Medical Home: An Algorithm for Developmental Surveillance and Screening
- The Medical Home [pdf]
- The Pediatrician’s Role in Development and Implementation of an Individual Education Plan (IEP) and/or an Individual Family Service Plan (IFSP)
- Providing Care For Immigrant, Homeless, and Migrant Children
- Role of the Medical Home in Family-Centered Early Intervention Services
- The Role of Preschool Home-Visiting Programs in Improving Children's Developmental and Health Outcomes

## General

- Handbook for Providers of Healthy Kids Services
- Illinois Chapter, American Academy of Pediatrics
- Illinois Department of Healthcare and Family Services
- Illinois Department of Human Services
- Illinois State Board of Education
- Maternal, Infant and Early Childhood Home Visiting (MIECHV) Benchmarks [pdf]
### Provider Training

- **Coordinating Care between Home Visiting and the Primary Care Medical Home**  
  (slide presentation)

- **Enhancing Developmentally Oriented Primary Care**  
  Available courses:  
  1. Coordinating Care Between Early Intervention and the Primary Care Medical Home  
  2. Developmental Screening and Referral  
  3. Domestic Violence Effects on Children: Detection, Screening and Referral in Primary Care  
  4. Identifying Perinatal Maternal Depression During the Well-child Visit: Resources for Screening, Referral, and Treatment  
  5. Social, Emotional, and Autism Concerns: Early Detection, Screening, and Referral

- **Illinois Early Intervention Training Program**

- **Illinois Health Connect Provider Education Webinars and Tools**

### Referral Resources

- **Child and Family Connections Offices**

- **Early Head Start National Resource Center**

- **Healthy Families Illinois**

- **Illinois Health Connect PCP Search** (provider search)

- **Illinois State Board of Education, Special Education Services**

- **Nurse Family Partnership**

- **Parents as Teachers**

- **Statewide Provider Database**
### Resources for Families

- **Family Voices**
  Family Voices is a national, nonprofit, family-led organization promoting quality health care for all children and youth, particularly those with special health care needs. Working with family leaders and professional partners at the local, state, regional, and national levels since 1992, Family Voices has brought a respected family perspective to improving health care programs and policies and ensuring that health care systems include, listen to, and honor the voices of families.

- **Child Care Resource and Referral** (CCRR)
  Information for parents looking for quality child care.

- **Health Care Visit Check List for Parents/Caregivers** [pdf]
  This check list was developed for families by Family Voices in collaboration and with the support of the federal Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration (HRSA). The Bright Futures for Families initiative was established to provide families with family friendly, child health and development information and materials based on the American Academy of Pediatrics (AAP) *Bright Futures: Guidelines for the Health Supervision of Infants, Children, and Adolescents (3rd ed.)*, used by health professionals across the country.

- **Milestones of Early Literacy Development**
  Created by Reach Out and Read, the Milestones of Early Literacy Development, offers information in an easy-to-read-grid on the developmental stages, both motor and cognitive, that lay the foundation for learning to read. Targeted to ages 6 months through 5 years, the Milestones include tips and guidance for providers, parents and caregivers on choosing books and reading aloud to children at different ages. The chart is available in both English [pdf] and Spanish [pdf].
APPENDIX E: LINKS TO FORMS FOR MAINTENANCE OF CERTIFICATION (FOR MEDICAL HOMES)

- 9 month run chart [pdf]
- 12 month run chart [pdf]
- 18 month run chart [pdf]
- Chart Review Form [pdf]
- Illinois Early Intervention Program Referral Fax Back Form [pdf]
- Medical Home Team Table of Responsibilities (Example) [pdf]
- MOC4 Process [pdf]
- PCP-coach activities [pdf]
- Standardized Illinois Early Intervention Referral Form [pdf]
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