



**Medical Home Implementation
CME Series
March - June 2009**

**#4: The Role of the Medical Home in
Family-Centered Early Intervention**

May 21, 2009

Featured Speakers:

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The Role of the Medical Home in Family-Centered Early Intervention (EI) Services: Overview

Larry Desch, MD, FAAP

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Medical School

Disclosure

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What is a Medical Home?

- An approach and process to providing care
- A partnership with the child, family, physicians and practice care staff
- An emphasis on the primary care practice as the “home” where the family and child can:
 - ***Feel recognized and supported***
 - ***Find a centralized base for medical care***
 - ***Find connection to other medical and non-medical community resources***
- Not just in Pediatrics anymore!

Components of Care in a Medical Home

"Sailing the Seven Cs" (Desch, 1986)

Medical care that is provided in the context of a medical home will be:

- Care that's accessible
- Centered on the Family
- Continuous
- Comprehensive
- Coordinated
- Compassionate
- Culturally effective



Who are Children with Special Health Care Needs?

“Children with Special Health Care Needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”

(Maternal and Child Health Bureau, 1995)

Next ...

Information about EI

- The EI philosophy
- The “EI law” and implementation
- Does it make a difference?
- Pediatric opportunities – The Medical Home!

Note: Children in EI are CSHCN!

What **IS** Early Intervention?

“Early intervention is the provision of support and resources to families of young children from members of informal and formal social support networks that both directly and indirectly influence child, parent and family functioning.”

-- Dunst, 2000

The Individuals with Disabilities Education Act (IDEA)

“Glue money”
to help states
COORDINATE



No choice!

SEA

LEA

Each state
names its
lead agency

Each state
determines its
local “entity”

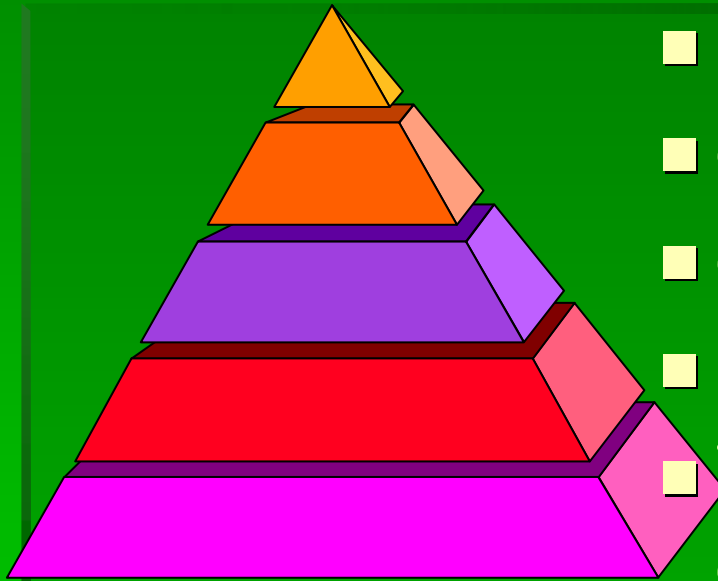
If states want
these planning
monies, they
have to follow
the Federal
Part C
policies!

Public Law 105-17, Part C



*Supports family-centered
early intervention for
children birth to three
years of age with
or at risk
(biological/environmental)
for developmental delays.*

Intent of Public Law 105-17, Part C



- Accessible Statewide*
- Comprehensive*
- Coordinated*
- Multidisciplinary
- Interagency program for eligible infants and toddlers and their families*

*** = Components of the Medical Home!!**

Which Children are Eligible for EI (Part C)?

- **Identified delay:**
 - in one or more areas of development:
 - cognitive
 - physical (motor, vision, hearing, or nutrition)
 - communication
 - social or emotional, or
 - adaptive
 - as measured by a developmental evaluation tool and informed clinical opinion;
- OR
- A **diagnosed physical or mental condition** that has a high probability of resulting in developmental delay

Core EI Services

Child Find
(Screening)

Evaluation &
Assessment

Service
Coordination
(which should
include
physicians)

Individualized
Family
Service Plan
(IFSP)

Procedural
Safeguards

Family
Support

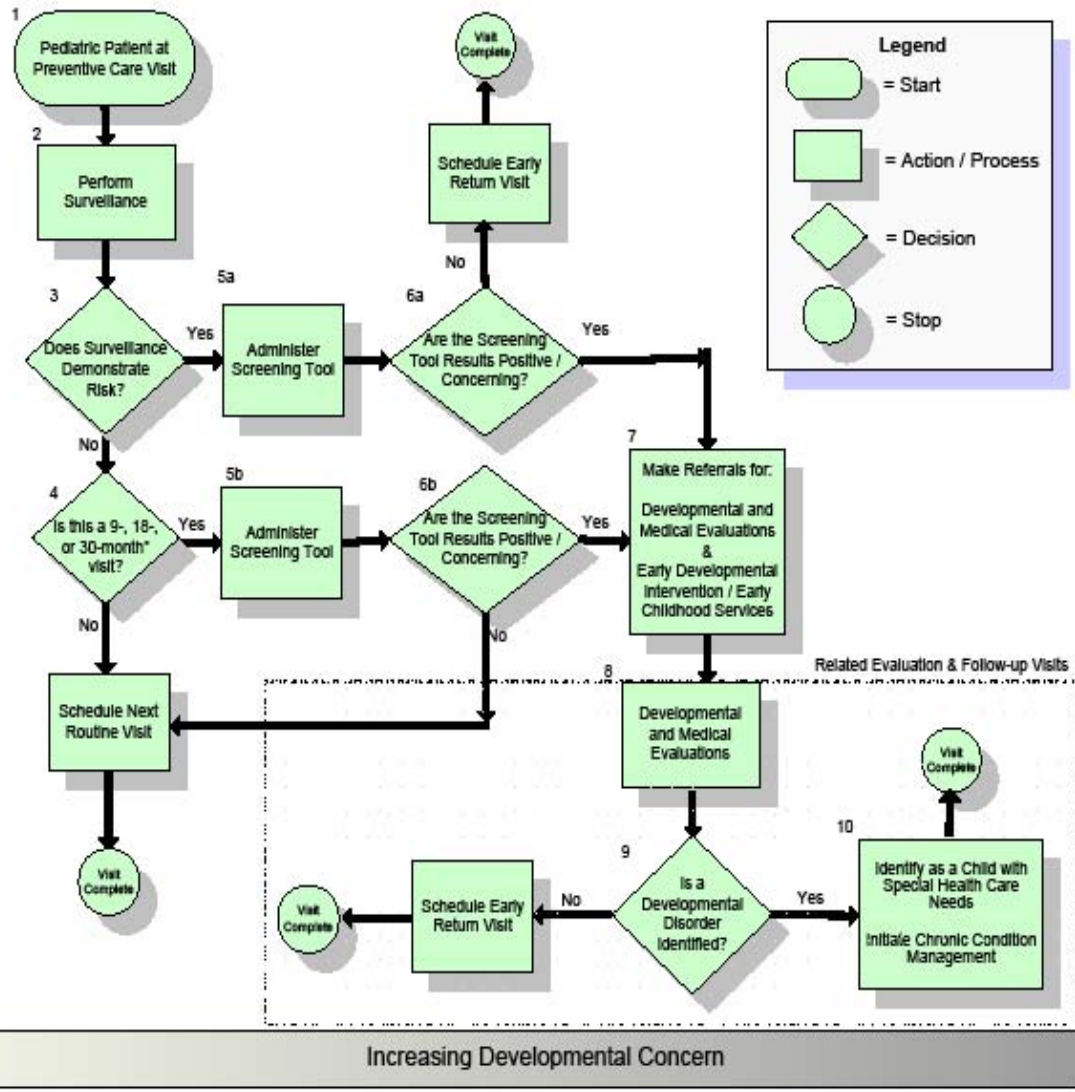
**These
are at
No Cost
to
Families**

Back to the Medical Home -- Developmental Screening

- All children, most of whom will not have identifiable risks or whose development appears to be proceeding typically, should receive periodic developmental screening using a standardized test

(AAP, *Pediatrics*, July 2006)

Developmental Surveillance and Screening Algorithm Within a Pediatric Preventive Care Visit



For an interactive version of this algorithm – where you can click on each shape for more information:

*Because the 30-month visit is not yet a part of the preventive care system and is often not reimbursable by third-party payers at this time, developmental screening can be performed at 24 months of age.

Surveillance and Screening Guidelines

- Perform developmental surveillance at every well-child visit
- Perform developmental screening using a standardized screening tool at 9, 18, and 30* months or when concern is expressed
- If screening results are concerning, refer to developmental and medical evaluations and early intervention services
- Follow up on referrals made and continually track child's developmental status

(AAP, *Pediatrics*, July 2006)

Next Steps: Evaluations then IFSP Development by EI

- If the child is found eligible by the evaluations to receive EI services, a team, which includes the parents, is chosen to complete an **Individual Family Service Plan (IFSP)** for the child. The purpose of the IFSP is to identify and organize formal and informal resources to assist a family in reaching outcomes (goals) for their child and for themselves.

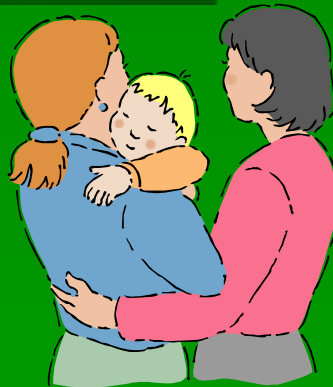
Pediatrician Input into the IFSP

1. During the IFSP meeting, the outcomes the family wants to achieve are identified.
2. The Medical Home physician can have input into the IFSP, by written or personal contact with the team and by being an advocate for the families' concerns.
3. The team decides what services are needed to assist the child and family to achieve these outcomes.
4. The family also chooses service providers who are enrolled with EI to provide services to address these outcomes.



The IFSP Must be . . .

- Respectful of family values
- Responsive to family priorities
- Supportive of family routines



Roles for the Medical Home Pediatrician after the IFSP



- Respond to identification of specific delays with medical work-up as needed (eg, an expedited hearing test if a language delay is identified)
- Referral to indicated Pediatric Subspecialists for medical diagnostic work-up and treatments
- Ensure patient receives services they need, both within and outside of EI (with care coordinator)
- Help families deal with potential reality of having a child with a long-term disability

Misconceptions about EI “Services”

- The federal law does **NOT** say that EI “specialized services” (like OT/PT/Speech) must be provided at no cost to families. These services can be provided at no cost, insurance may be charged, or families might have to pay a sliding scale fee.

more on this from the next speaker...

Intervention vs. Services

- Intervention and services are not the same.
- Children need maximal intervention, not maximal services.
- EI (and the Medical Home's job) is to support families in carrying out intervention.
- "EI" is the process of adults providing support to adults on behalf of their children.

-- Adapted from McWilliam, 2002

Some Myths About Services

- *Certain diagnoses require certain services*
- *More is better*
- *Have a need = get a service*
- *Professionals have “magic hands”*



Illinois: Medical Home & EI

Lessons learned from the IL Medical Home project:

- Parent partner is crucial part of health care team
- Care coordination (information sharing) helps *all* parties
- Practices can use strategies and tools (assigned care coordinator, referral tracking) to be better partners with EI

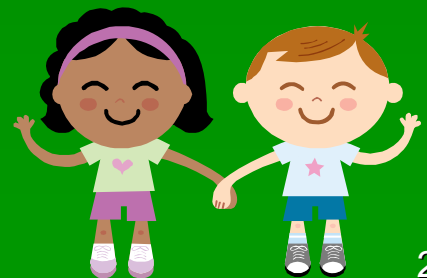
Challenges that needed to be addressed:

- “Language” of EI and primary care are different
- Medical homes coordinate many different services and specialists; they need to learn strategies and improved referral processes to enhance quality of care and coordination of care especially with EI

Does EI Work?

Most research says a qualified “yes”!

- Helps socially disadvantaged children
- Improves family adaptation and functioning
- Improves outcomes in children with underlying biological conditions
- Fewer special education and other services later in life



EI Effectiveness

- As a field, we've come to a consensus on values - EI should be:
 - family-centered
 - interdisciplinary
 - community-based
- We agree that the early years constitute a unique opportunity.
- We agree that it's our responsibility to provide early intervention – it's the right thing to do.

References

- Council on Children with Disabilities, DUBY, JC, lead author. Role of Medical Home in Family-Centered Early Intervention Services, *Pediatrics*, 120(5):1153-1158. November 2007
- Council on Children with Disabilities. Lipkin, P, DUBY, JC, Biondich, P, Hagan, J, Duncan, P, Cooley, C, et. al. Identifying Infants and Young Children With Developmental Disorders in the Medical Home: An Algorithm for Developmental Surveillance and Screening, *Pediatrics*, 118:405-420, July 2006
- Majnemer, A. Benefits of Early Intervention for Children with Developmental Disabilities, *Seminars in Pediatric Neurology*, 5(1):62-69, March 1998
- Multiple Resources available at:
 - <http://www.medicalhomeinfo.org/health/EI.html>

And, a big “thank you” to Dr. John DUBY for the use of many of the previous slides.

Understanding the Role of the Early Intervention Program

Jon Ashworth, MDiv, MA, LPC

Social-Emotional Specialist/Consultant – Child and Family
Connections #2 (IL Early Intervention Program)

Consultant/Quality Improvement Team Facilitator –
Illinois Chapter, American Academy of Pediatrics
(IL Medical Home Project; EI/Primary Care Project)

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Overview & “Behind the Scenes” Perspectives

- Understanding the charge of Early Intervention staff from the perspective of state guidelines and expectations (specific example of the Illinois EI Program)
- Gaining a larger and broader perspective of the collaboration between EI and Primary Care (current collaborative project between ICAAP, Advocate Health Care, and Illinois EI Program, funded by The Commonwealth Fund – referenced at end of section)

Focus and Scope of Early Intervention Philosophy

1. Children in need of Early Intervention (EI) services are identified and can access services.
2. The primary goal of EI is to support families in promoting their child's optimal development and to facilitate the child's participation in family and community activities.



Focus and Scope of Early Intervention Philosophy

3. The focus of EI is to encourage the active participation of families in the therapeutic process by imbedding intervention strategies into family routines. It is the parents who provide the real early intervention by creatively adapting their child care methods to facilitate the development of their child, while balancing the needs of the rest of their family.

Focus and Scope of Early Intervention Philosophy

4. EI requires a collaborative relationship between families and providers, with equal participation by all those involved in the process. An on-going parent professional dialogue is needed to develop, implement, monitor, and modify therapeutic activities.
5. Intervention must be linked to specific goals that are family-centered, functional, and measurable. Intervention strategies should focus on facilitating social interaction, exploration, and autonomy.

Focus and Scope of Early Intervention Philosophy

6. Intervention shall be integrated into a comprehensive plan that encourages transdisciplinary activities and avoids unnecessary duplication of services. The plan shall be built around family routines, with written home activity programs to encourage family participation in therapeutic activities on a daily basis.



Focus and Scope of Early Intervention Philosophy

7. Intervention should be monitored periodically to assure that the strategies implemented are successful in achieving outcomes.
8. Children and their families in the Early Intervention System deserve to have services of highest quality possible. High standards will be set for the training and credentialing of administrative and intervention staff. Training, supervision, and technology will be focused to achieve excellence.

Service Provision in EI: Shaping Family Expectations

An EI Service Provider is:

**An educator and
resource provider**

**A hands-on link
to services**

**Your partner in your child's
services, ready to discuss what's
important to your family.**

**An assistant to your family who
can give advice about how to
integrate activities into your daily
routine that will enhance your
child's development.**

Service Provision in EI: Shaping Family Expectations

Examples of EI Service Providers include:

- Pediatrician or other Physician
- Speech Therapists
- Occupational Therapists
- Physical Therapists
- Developmental Therapists
- Social Workers, Counselors, Psychologists
- Registered Dieticians
- Vision Specialists



Service Provision in EI: Shaping Family Expectations

This teaming and empowering approach must be explained to families considering the possibility of entering into the Early Intervention System.

Sometimes, families are given the impression that Early Intervention is a state-run, federally funded therapy clinic (using federal funds to offer rehabilitative, clinic-type services to children who are eligible).

Understanding and Addressing Common Misconceptions regarding EI

Scenario #1 – All EI services are free.



Clarification #1 – Families will be expected to participate through the payment of a family fee based on an annual income sliding fee scale. Although the family fee is an annual assessment, payment expectations will never exceed the amount the EI program has paid to the family's service providers. It should also be noted that EI evaluations are free.



“Where did I get the idea that all Early Intervention services are free?”

“You were not totally off base. Until legislation in September of 1997, all Early Intervention services were free. However, that is no longer the case.”



What is Free* & What is Not Free in Early Intervention

What is Free?

1. EI evaluations, both initial & follow-up
2. Basic service coordination
3. IFSP meetings
4. Transitions to school district
5. EI interpreter services
6. EI parent liaison services

What is Not Free?

1. Ongoing therapy services, including assistive technology

* = The term “free” is being used to designate items that would not be subject to the annual family participation fee. It is possible that items would be subject to a family fee and the family’s size and income would generate a family fee of \$0.

Understanding and Addressing Common Misconceptions regarding EI

Scenario #2 – My private insurance will not be affected by my participation with the EI System.

Clarification #2 – Private insurance must be used for EI services, with safeguards for families and exemptions under certain circumstances.

Adapted from
A Family's Introduction to EI 2007

Use of Insurance – One More Note

The Early Intervention program is the payer of last resort!

This means that any other source that would be authorized to make payment for EI services must be tapped before the EI system.

These resources include a family's private insurance, along with other forms of public insurance that the family may currently have or for which they may be eligible.



Understanding and Addressing Common Misconceptions regarding EI

Scenario #3 – My child’s pediatrician gave me a prescription for speech therapy 2x per week. Why is my child’s IFSP team telling me that my child can only have speech therapy 1x per week. Don’t they respect our pediatrician’s medical advice?

Clarification #3 – Early Intervention is not a medical or rehabilitative program. It is a developmental program with a coaching model of service provision. Prescribing the frequency of services is not the role of the pediatrician within the EI program.

Adapted from
A Family’s Introduction to EI 2007

Helping Families Understand EI and Consider Their Options

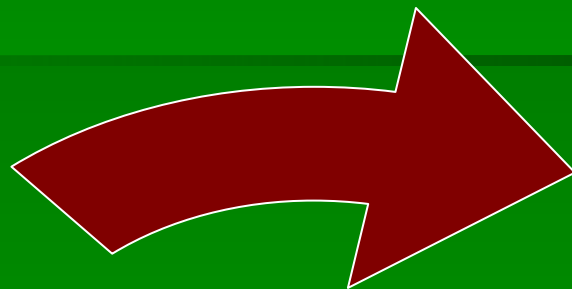
1. Families should understand their level of responsibility within the Early Intervention System.
2. Families should understand that the EI System is not operated in the same manner as a private therapy agency (federal timelines, large caseloads, etc.)
3. EI is a very good program for many families. But it is not the right program for every family. Some families may prefer to use private insurance for private service (eg, torticollis).

Helping EI Therapists Understand the Illinois EI System and its Philosophy

1. Many EI Therapists have a long history of working in hospital, clinic, and/or other medical settings. These experiences often carry over into their work within EI.
2. Many EI Therapists operate with a philosophy of “doing therapy to children” and “more is better.”
3. There have been some good pockets of professional development around the state in consultative and coaching models of service provision.

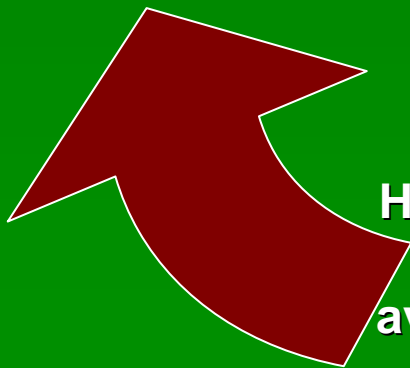


Preparing Families for the Future: Anticipating Transitional Needs



Helping families think about
resources available to
them **through** the EI System

Helping families think about
resources available to
them **beyond** the EI System



Helping empower families
to explore resources
available to them through
their local &
surrounding communities



Ongoing progress monitoring for the family regarding the child's progress and options

1. Embedded within Early Intervention philosophy
2. Partnership between Family, EI therapists, Service Coordinator & the Primary Care Medical Home
3. Required annual review (IFSP lasts for 12 months)
4. Redetermination of eligibility (including global evaluation)

Building Bridges Between EI and Primary Care Physicians

Coordinating Care Between EI and Primary Care Practices

- AAP Illinois Chapter, Advocate Health Care's Healthy Steps for Young Children Program
- Enhancing Developmentally Oriented Primary Care
- Funded by The Commonwealth Fund
 - * 4 pilot EI programs
 - * 8 pilot Primary Care practices
 - * testing curricula designed to build bridges
 - * statewide and potentially national implications

Strategies to Form Partnerships, Encourage Referrals, and Improve Communication with Early Intervention

Anita Berry MSN, CNP, APN

Director, Healthy Steps for Young Children Program

Advocate Health Care

Project Director, Enhancing Developmentally Oriented
Primary Care (EDOPC)

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Why Refer vs. Wait and See

- Satisfaction - Parents are critical of providers for waiting too long to make the referral
- Early Intervention works
- Cost saving – may never need special education services

Equal Access

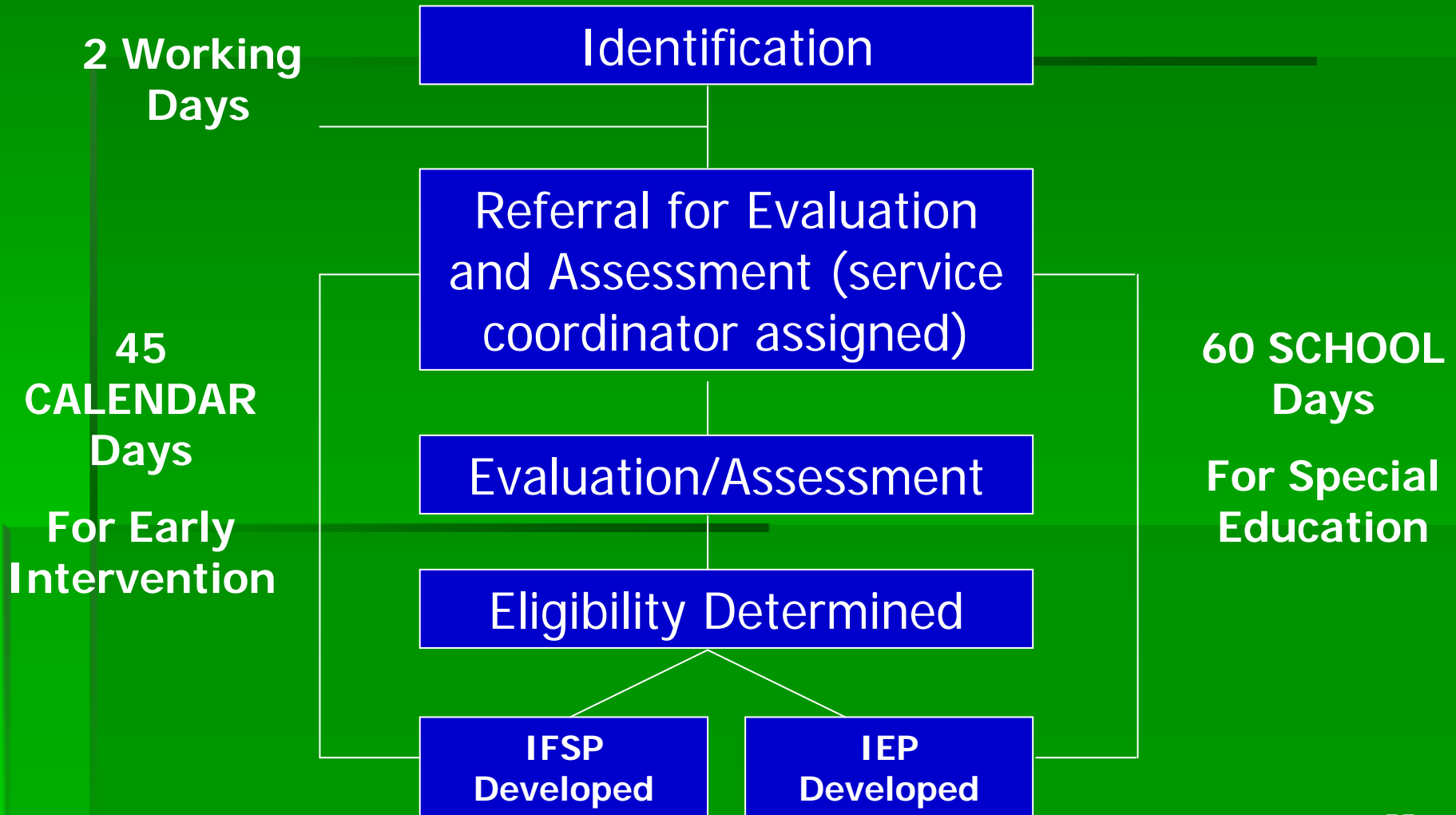
- Advocate for Early Intervention services for all children in need
- Participate in Child Find activities

Who Can Refer?

- Parents
- Primary care providers
- Grandparents
- Child care
- Neighbors
- Anyone!



Early Intervention: When to Refer



National Early Intervention Longitudinal Study

- Age at first concern later for developmental delays than diagnosed conditions
- Time between first concern and development of IFSP longer for children with developmental delays than diagnosed conditions
- Male children entered services later than female
- White children entered services later than other ethnicities

Provide Information to IFSP

Collaborate with Family & Care Coordinator:

- Provide medical input into development of IFSP
- Ensure goals are functional in nature



Role of Primary Care Providers

- Identify delays or potential risks by screening all children routinely.
- Timely referral of children who are delayed or are at risk for delay.
- Follow up with family to ensure patient receives services they need.
- Respond to identification of specific delays with medical work-up as needed (e.g. a hearing test if a language delay is identified).
- Support families by helping them deal with potential reality of having a child with a disability.

Referral Resources: Overview

- Prevention Programs
 - at risk
- Early Intervention
 - birth to age 3
 - suspected delay
 - qualifying condition
- Special Education
 - ages 3 to 21



Prevention Programs

- Early Head Start
- Head Start
- Parents Too Soon
- Healthy Start
- Healthy Families
- Safe From the Start
- Prevention Initiatives and Parent Training

How to Make A Referral

- Appoint someone in office to coordinate referrals
- Use AAP and US Department of Education Office of Special Education referral form – individualize to meet your needs *(see next slide)*
- Call, fax, give a prescription – do all three to ensure follow through



Universal Referral Form

www.medicalhomeinfo.org/health/EI.html

Early Intervention Program Referral Form

Please complete this form for referring a child to Early Intervention (Part C) if you prefer to do so in writing. Also please indicate the feedback that you want to receive from the Early Intervention Program in response to your referral. Diagnosis of a specific condition or disorder is not necessary for a referral.

Parent/Child Contact Information

Child Name: _____
Date of Birth: ____/____/____ Child Age: (Months) _____ Gender: M F
Home Address: _____
Parent/Guardian _____ Relationship to Child: _____
Primary Language: _____ Home Phone: _____ Other Phone: _____

Reason(s) for Referral to Early Intervention

(Please check all that apply)

- Identified condition or diagnosis (e.g., spina bifida, Down syndrome): _____
 Suspected developmental delay or concern (Please circle areas of concern):
Motor/Physical Cognitive Social/Emotional Speech/Language Behavior Other _____
 At Risk (Describe risk factors): _____
 Other (Describe): _____

Referral Source Contact Information

Person Making Referral: _____ Date of Referral: ____/____/____
Address: _____
Office Phone _____ Office Fax: _____ E-mail _____

Early Intervention Program Contact Information

Program Name: _____
Address: _____ City: _____ State: _____ Zip: _____
Office Phone _____ Office Fax: _____ E-mail _____

Feedback Requested by the Referral Source

Date Referral Received: ____/____/____ Date of Initial Appointment with Child/Family: ____/____/____
Name of Assigned Service Coordinator: _____
Office Phone: _____ Office Fax: _____ E-mail: _____

After initial appointment, please send the following information:

- Status of Initial Family Contact Changes in Services Being Provided
 Developmental Evaluation Results Periodic Progress Reports/Summaries
 Services Being Provided to Child/Family Other (Describe): _____
(Including: names of providers and frequency of services)

Release of Information Consent

I, _____ (Print name of parent or guardian), give my permission for my pediatric health care provider, _____ (print provider's name), to share any and all pertinent information regarding my child, _____ (print child's name), with the early intervention program.

Parent/Legal Guardian Signature _____ Date: ____/____/____

This form is available on the National Center of Medical Home Initiatives for Children with Special Needs website. Go to <http://www.medicalhomeinfo.org/health/EI.html> to download this form and learn more about Early Intervention.

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2007;120(5)

This form was developed as part of a collaboration between the American Academy of Pediatrics and the Tracking, Referral and Assessment Center for Excellence, Orelena Hawks Puckett Institute, Inc. The development of this form was supported, in part, by funding from the US Department of Education, Office of Special Education Programs, Research to Practice Division (H324G020002).

Maintain a Database/Log

- Central Medical Database contains
 - ✓ Pertinent diagnostic information
 - ✓ Consultative information
 - ✓ Copy of referral form



Developmental Referral Log

DATE	INFANT'S NAME/DOB	MOM'S NAME	ASQ SCORE	FOLLOW-UP REFERRAL	COMMENTS

What will happen after you refer?

- 1. Intake**
- 2. Multi-disciplinary developmental evaluation**
- 3. Determination of eligibility**
- 4. Development of IFSP (within 45 calendar days)**
- 5. Receipt of services (within 2 weeks, generally)**

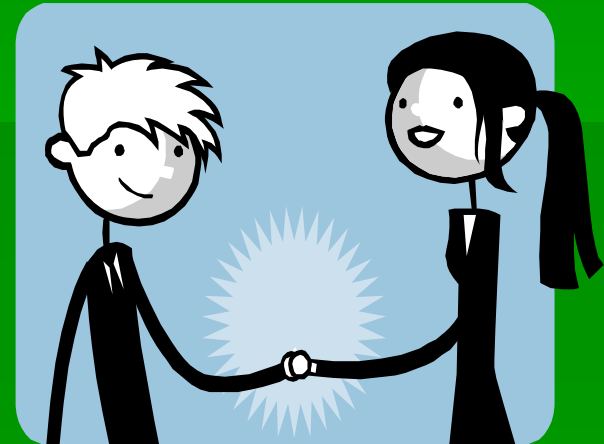
Coordinating the Health Component of Services

- Medical Providers should keep a log of referrals made to EI
- Medical Providers need to be aware of
 - What services a child is receiving
 - How often they are receiving services
 - When they should follow up with the family

Developing and Nurturing Partnerships

Effective Partnerships Built on:

- knowledge
- familiarity and equality among partners
- good communication
- understanding of roles
- effective negotiation
- consistency
- stability



Finding the Words



“There are therapists who can come to your home to help your son learn to _____ and teach you ways to help him progress. Would you be interested in something like that?”

More Information:

<http://www.medicalhomeinfo.org/health/EI.html>

Find an EI Contact in Your State:

<http://nectac.org/>



Questions?