Early Intervention for Children From birth to Age 3 in Pa.

Special focus: Children involved in the Child Welfare System

Janet Stocco & Janet Stotland
Education Law Center-Pa
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Infant/Toddler Early Intervention (EI)

• Eligibility for EI
• Overview of process:
  - Step 1: Referral
  - Step 2: Multi-Disciplinary Evaluation
  - Step 3: Tracking or IFSP
• Consent / Confidentiality Rules
  - Parents vs. Surrogate Parents
  - Parental Rights
• Step 4: Transition to preschool EI
• Case Study
What is it?

• Services to children Age 0-3rd Birthday
  - State: Dept. of Public Welfare (DPW)
  - County Mental Health/Mental Retardation (MH/MR) Agencies are responsible for EI but the County usually contracts with other agencies to provide services
    • Philadelphia also contracts out its intake and evaluation functions to ChildLink
  - Laws (federal and state)
    - Act 212: 11 P.S. § 875 / 55 Pa. Code Ch. 4226
Who is Eligible?

- Children age birth to 3rd birthday
- “Developmental Delay” in at least one of these areas of development:
  - Cognition
  - Communication
  - Social and emotional
  - Adaptive behavior
  - Physical (including vision and/or hearing)
Who is eligible? cont’d…

- **How is Developmental Delay Diagnosed?**
  - 25% delay for child’s age
    - via appropriate diagnostic instruments/procedures
  - *Tests reveal 1.5 standard deviations below mean*
    - on accepted standard tests for infants/toddlers
  - *Diagnosed physical/mental condition that has a high probability of resulting in a delay*
    - Ex: fetal alcohol syndrome, Down Syndrome, metabolic disorders, seizure disorders, etc.
  - *Informed clinical opinion*
    - especially if standardized tests are not available for child’s chronological age or the developmental area
“Child Find” Duty

• DPW & MH/MR agencies have a legal duty to locate eligible children, including:
  - Children who are homeless &
  - Children who are wards of the State

• Mandatory referrals for evaluation:
  The State must have a system to refer child if:
  - Substantiated case of child abuse or neglect
  - Affected by illegal substance abuse or withdrawal due to prenatal drug exposure
  - Substantiated trauma from family violence.
State Law: Child Find

**ADDS:**

- **Definition of “at risk”:** (category of children who also should be tracked by DPW)
  - Birth weight under 1,500 grams (3.3 lbs)
  - Neonatal intensive care unit
  - Born to chemically dependent mother
    - And referred by doctor and parent
  - Seriously abused and neglected
    - As substantiated and referred by children & youth agency
Step 1: Referral

• **Who can refer?**
  - Hospitals, doctors, parents, day care settings, social service agencies, etc.
  - State required to provide info. at places listed above describing EI services

• **How?**
  - In Philadelphia
    • Call ChildLink 215-731-2110
  Other PA
    • Call CONNECT 800-692-7288
Referrals cont’d...

• **REFERRAL ≠ Permission to evaluate!**
  - **MH/MR must** get permission from the child’s “parent” to conduct an evaluation
    • Parent consent must be informed, voluntary, written

• **Upon referral of child, MH/MR must:**
  - Appoint a service coordinator ASAP
  - Within **45 days**, complete the multidisciplinary evaluation & develop
    • a service plan (IFSP) if child is eligible; or
    • Plan for further assessment and tracking if child is “at-risk” but not eligible for services
Step 2: Multi-Disciplinary Evaluation:

• **Conduct of Evaluation:**
  - Initial eval. must be performed by someone not involved in providing services to the child
  - Based on informed clinical opinion
  - Conducted by persons trained in assessments
  - Non-discriminatory, in parent’s native language
  - Must include
    • Review of relevant health status/history
    • Child’s level of functioning and unique needs in each developmental area
    • Voluntary Family assessment (personal interview to determine resources, priorities, concerns of family)
Multi-Disciplinary Evaluation cont’d…

- **Timelines**
  - Must be done in time for an IFSP to be developed within **45 days** of referral
    - If cannot complete in time, EI agency must document why and create an “interim’ IFSP (service plan)
  - Must conduct further MDEs at least **annually**
  - Written report to parents within **30 days**

- **Note:** may provide services while awaiting the evaluation
  - Use an “interim” IFSP
  - Parent must consent
Step 3: Tracking
(if “at risk” but not eligible for EI)

• **Tracking Services:**
  - MH/MR must contact child’s family by phone, in writing, or in a meeting ≥ once every 3 months
    • MDE may suggest more frequent contact
  - Must use a standardized developmental checklist to review need for:
    • Further tracking
    • Further eval/re-eval for EI services eligibility
  - Tracking requires parental consent!
    Parent can request less frequent or NO contact
Step 3: IFSP
(if eligible for EI)

- **IFSP:** individualized family service plan
  - Services must be free & based on the evaluation and assessment data
  - Written by a team of individuals:
    - Parent of infant/toddler (can invite others)
    - Service Coordinator
    - Person directly involved in the evaluation
    - Persons providing services to infant/toddler
• What is included in the IFSP?
  - Current levels in the 5 developmental areas (& results of family assessment, if consented to)
  - List of Major outcomes child should achieve & how to measure child’s progress
  - Name of service coordinator
  - Services child/family will receive
    • How often
    • Where: Should be in “natural environment” (including home, community settings); if not, IFSP must explain why not in natural setting
    • Whether service is directly to the child or will be consultation with someone working with the child
IFSP cont’d…

• **Types of services (to child/family) include:**
  - Special instruction, speech-language, occupational & physical therapies, audiology, nursing, nutrition, vision, assistive technology devices and services
  - Psychological services (including counseling)
  - Social work services (to help family help child)
  - Medical (for diagnosis & if necessary for child to benefit from another EI service)
  - **Service Coordination - (all receive this)**
    - Facilitate assessments, development and review of IFSPs, and transition to pre-school services

  Coordinate/monitor delivery of EI services & more (even if services are not the responsibility of EI).
IFSP cont’d...

- **Parent Consent to IFSP services:**
  - Informed, voluntary, written consent required
  - Parent can refuse consent to part of the IFSP without jeopardizing rest of promised services

- **Timelines:**
  - Services must start within 14 days of IFSP
    - Can extend at parent’s request, based on the child’s needs, or at recommendation of the team including the parent.
  - Must review IFSP every 6 months
    - Is progress being made toward outcomes?
    - Should outcomes or services be changed?
  - Must meet to review/revise IFSP ≥ annually (based on current evaluations)
Who is a “parent”?

- Law defines “parent” as:
  - Natural or adoptive parent
  - Guardian/legal custodian (but not the State)
  - Person acting in place of parent (such as grandparent/stepparent living with child)
  - Surrogate Parent
  - Long term foster parent if parent’s education rights have been terminated
Surrogate Parent Rules
Note: These are the rules for infants/toddlers, not older kids

• When does an infant/toddler need a surrogate parent?
  - Parents can’t be identified
  - Parents’ whereabouts unknown OR
  - Child in custody of children & youth and
    • Parents can’t be identified / found
    • Parents’ rights have been terminated or
    • Parents are dead and there’s no other parent
Surrogate Parents cont’d

Note: These are the rules for infants/toddlers, not older kids

• **Who appoints surrogates?**
  - MH/MR agency

• **Who can they appoint?**
  - Adult with knowledge/skills and no conflicts
  - Example: Foster parent
    (Children & Youth Agency or DHS must agree to the appointment, but it’s usually the best choice!)

• **Who can NOT be appointed?**
  - Employee of any State agency
  - Employee of EI agency or any agency providing services to the family or the child
  - Employee of private foster care agency serving the child
“Parent” rights in infant/toddler EI system

- To written prior notice of:
  - Initiation or change to evaluations, services, placement; must be in parent’s native language when feasible

- To consent (or refuse to consent) to:
  - Initial evaluation
  - Referral to “at-risk” tracking system
  - Initiating/changing any EI service(s) - the refusal to accept any one service can not jeopardize other services

- To request IFSP meeting at any time
- To review child’s EI records
- To confidentiality of information
“Parent” Rights cont’d...

Options for Resolving Disputes

• **Conflict Resolution** (voluntary)
  - Contact MH/MR orally or in writing
  - Meeting with county administrative staff must be held within 7 days

• **Mediation** (voluntary)
  - Contact ODR (800-992-4334)
  - Must take place within 10 days
  - Discussions are confidential
  - No lawyers present
Options for Resolving Disputes
cont’d…

• **Complaint**
  - Legal violations (ex: timelines/IFSP not followed)
  - How: in writing, to OCDEL, 333 Market Street, 6th Floor, Harrisburg, PA 17126-0333 or call 717-346-9320
  - 60 calendar days to investigate/issue decision

• **Due process**
  - Disputes over eligibility, amount/type of services
  - How: letter to MH/MR (or service coordinator)
  - 30 calendar days to hold hearing/issue decision

• Parent may be offered conflict resolution and/or mediation but those are voluntary & can’t delay hearing
Resolving Disputes
cont’d…

• During conflict resolution, mediation, and/or due process proceedings:
  - Child must continue to receive EI services currently being provided unless parent & MH/MR agree to a change
  - If child is new to the system, during dispute child receives any services parent & MH/MR can agree upon
Step 4: Transition to pre-school EI system

- **Key differences in Pre-School EI:**
  - **Responsible Agency**
    - PDE and MAWA agencies (usually the Intermediate Unit (IU), in Philly & Chester it is Elwyn)
  - **Eligibility:** from age 3 to “beginners”
    - Child must have a developmental delay or a qualifying disability (autism, MR, sensory impairment, emotional disturbance, etc.)
      - Note: delay must be shown, can’t be based on informed clinical opinion or potential future delay
      - **AND**, as a result of the delay/disability, require specialized instruction
Step 4: Transition cont’d…

- **Key differences in Pre-School EI:**
  - **Services**
    - No nutrition counseling or service coordination
    - (But, may get service coordination if qualify for MH/MR &/or Elwyn offers some service coordination)
  - **Program:**
    - Individualized Education Plan (IEP)
  - **Placement:**
    - Infant/Toddler EI: “natural environments”
    - Pre-school EI: “least restrictive environment”
Step 4: Transition cont’d…

• Transition Process:
  - Before child turns 3, IFSP must address child’s transition needs (services to prepare for change)
  - If parent consents, past IFSPs & evaluations are shared with preschool EI agency
  - At least 90 days before 3rd birthday:
    • (If family consents) MH/MR, preschool EI agency and family meet to discuss the services child will receive upon turning 3 and to develop an IEP for the child.
Step 4: Transition cont’d…

• **Special Transition Process:**
  - Children who are identified by MH/MR within 60 days of their 3rd birthday are evaluated by the preschool EI agency

• **Disputes re: proposed preschool IEP:**
  - The child has a right to continue receiving the services in the last-agreed-to IFSP until the dispute is resolved through the hearing process
  - Although the same type and amount of services must be provided, the service provider may change (no right to the same staff)
Surrogate Parents in Pre-school EI system

• Who can appoint?
  - The preschool EI agency
  - Or the juvenile judge involved in the child’s case

• Who can be appointed?
  - Generally, rule is the same, except that foster parents can be appointed without approval of DHS/Children&Youth Agency
CASE STUDY

• Jane is a 18-month old toddler whose mother is an alcoholic and whom you suspect was drinking heavily when she was pregnant with Jane. You also know that Jane was a preemie. The SCOH worker assigned to the case has noticed that Jane can only speak about 5 words (hi, bye-bye, up, uh-oh, and ma-ma).
  • Question #1: Is this child entitled to any services from the EI system?
  • Question #2: Following a referral to ChildLink, what does the agency have to do?
  Question #3: If child gets an IFSP, when do services have to start?
Case Study cont’d...

• Jane is evaluated and found eligible based on fetal alcohol syndrome (she only has a 20% delay in speech). She is given a special instructor for speech therapy and seems to improve over time but you notice she has attention difficulties in her early Headstart and she frequently has temper tantrums. In the past year, she entered foster care two miles away from her mom’s home.

• When she is 2 ½ years old, a reevaluation by a special educator and a speech therapist reveals normal speech, no cognitive delays. The evaluation discusses her disruptive behaviors and tantrums by suggesting the family contact CBH.
Case Study cont’d…

- At the transition meeting 90 days before her 3<sup>rd</sup> birthday, Elwyn states that because Jane has no cognitive deficits she does not need specialized instruction and is therefore not eligible for preschool EI services.
  
  - Question #4: Who should have been invited to the transition meeting as Jane’s “parent”? What can you do (if anything) if they weren’t invited?
  
  - Question #5: Is Jane eligible for preschool EI services?
  
  Question #6: While Jane’s “parent” and Elwyn fight about this, what happens to Jane’s services?