Early Intervention and Speech-Language Pathology: A Training for Family and Collaborative Professionals

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Introductions
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Illinois LEND
LEND

- Leadership Education in Neurodevelopmental and Related Disabilities
- Graduate-level interdisciplinary training
- 52 LEND programs in 44 states
  - National network that shares information and resources
- Complete 300 hours of policy, research, leadership, community, and clinical work
  - Weekly lectures, clinical sessions, community volunteering, projects, research, and more

LEND

- LEND’s mission:
  - Improve the health and wellbeing of individuals with disabilities
    - Autism Spectrum Disorder (ASD)
  - Advocate for and with individuals with disabilities
  - Advance knowledge and skills of all child health professionals
  - Provide high-quality interdisciplinary education
  - Provide health professionals with skills
  - Promote innovative practices

Illinois LEND

- Chicago, IL
- 29 trainees, 13 disciplines
  - Occupational therapy, physical therapy, pediatrics, psychology, disability studies, public health, special education, nursing, applied behavior analysis, social work, speech-language pathology
  - Family members of individuals with disabilities and self-advocates
- Rush University, University of Illinois at Chicago, University of Illinois at Urbana-Champaign, and Southern Illinois University
Early Intervention
Today’s Objectives

1. Describe what Early Intervention (EI) is
   ○ How to access services
   ○ Explain the professionals’ (i.e. Speech Language Pathologists (SLPs)) roles and services in Early Intervention

2. Know different ways to spread advocacy

3. Aware of different programs within The Arc relating to Early Intervention
What is Early Intervention (EI)?

According to Centers for Disease Control and Protection (CDC):

“Early Intervention is the term used to describe the services and supports that are available to babies and young children with developmental delays and disabilities and their families. [Early Intervention] can have a significant impact on a child’s ability to learn new skills and overcome challenges and can increase success in school and life.”

Federal Law

Part C of IDEA: Individuals with Disabilities Act (as of 1997)

- Ages for services: birth-3
- Goal: Help families meet the developmental needs of their child with a disability or delay
- Annual funding to each state depends on the annual census
  - Children from birth-2 at the time

Eligibility

3 ways to be eligible:

1. 30% delay in one or more areas of development
   - Physical
   - Cognitive
   - Communication
   - Social
   - Emotional

2. Documented medical condition as determined by the IDHS, Bureau of EI

3. Considered “at risk”
Eligibility continued..

What does “at risk” mean?

- Parent with severe mental disorder or with a developmental disability
- Or at least 3 of the following:
  - Current substance abuse (or during pregnancy) by primary caretaker
  - Primary caretaker less than 15 years of age
  - Current homelessness
  - Chronic illness of primary caretaker
  - Primary caretaker with less than 10th grade education
  - Documented abuse and neglect when child is not removed from the abuse/neglect circumstances
Accessing

● Where to start?
  ○ Illinois Early Intervention Program to request an evaluation
  ○ (800) 323-4769

● Who can refer?
  ○ Parent
  ○ Pediatrician
  ○ Doctor referral is not necessary

● Parent must provide consent for further evaluations/services
● Service coordinator established

Assessment

- Trained professional conducts assessments to assess if delays are present
- Professionals:
  - Psychologist
  - Neurologist
  - Speech-Language Pathologist (SLP)
  - Physical Therapist (PT)
  - Occupational Therapist (OT)
- Family-based approach
- Depends on the concerns for the child

Developing a plan

- Timeline from initial referral to service plan: 45 days
- Individual Family Service Plan (IFSP)
  - Meeting with Service Coordinator, family, other professionals on the team
- Included in the plan:
  - Reviewing parents’ concerns
  - Establish goals
  - Identify strategies
  - Identify necessary services/timeline
IFSP Goal Example

SECTION 3: FUNCTIONAL OUTCOME # 1
(May be used as an Annual goal statement for Part B Preschool Services)

***Family Priorities (Concerns)***

we want Cecilia to sit safely by herself

What do we want for Cecilia and our family? (What does the family want and why?)

Cecilia will sit safely by herself so that she can play without falling.

How will we achieve this outcome? (List strategies and/or activities designed to facilitate the achievement of the outcome and/or steps to be taken to link us to services and/or secure funding for services if not required to be provided by the Part C Early Intervention System)

- Model techniques to encourage Cecilia to spend time on her belly
- Demonstrate techniques for Cecilia to move in and out of some certain positions during floor play
- Identify motivating toys to encourage her exploration

What Early Intervention and/or other service and supports would help us with this?

- Family
- Service Coordinator
- Physical Therapist

Fund Source

Upon review, how are we doing? Has our outcome been achieved? Should our outcome, strategies, activities and/or services change? If so, how? Written parental consent required to change any services.

FOR EARLY INTERVENTION PARTICIPANTS ONLY The primary setting for young children is within the context of the family, their home, their community, lifestyle and daily activities, routines and obligations. To the extent appropriate, services must be provided in the types of settings in which young children without and their families would participate. Are all Part C EI services needed to achieve this outcome being provided in natural environments?

Yes ___ No __

Note regarding Fund Source: All Part C Early Intervention Services must be preauthorized. For all other services identified as needed but not required to be provided by the Part C Early Intervention System, indicate the fund source(s). Instead, ORCC, private insurance which is either responsible for payment or from which payment is being sought.

IL441-4250 (R-06-07) Page 4 of 11
Types of services that may be included in EI:

- Assistive technology
- Audiology/aural rehabilitation
- Developmental therapy
- Family training and support
- Health consultation
- Medical services (only for diagnostics)
- Nursing
- Nutrition
- Occupational Therapy

- Physical therapy
- Psychological services
- Service coordination
- Sign language or cued language
- Social work
- Speech-Language Pathology
- Transportation
- Vision
- Translation/interpretation
Speech-Language Pathology Services

- What are they?
  - Targeted areas
- Who does it?
- Where does it happen?
- Why is it important?
Speech-Language Pathology Services: What are they?

- Assessment, treatment, and prevention of **speech**, **language**, **cognitive**, and **feeding/swallowing** disorders and difficulties
- For people of all ages
  - From babies in the NICU to adult end-of-life care
What is SPEECH LANGUAGE PATHOLOGY?

SPEECH
- The expression of the ability to express thoughts and feelings by articulation sounds.
- Providing multi-faceted therapy for individuals with congenital or acquired fluency disorders.
- Providing auditory training for individuals with hearing loss or auditory processing disorders.
- Using knowledge of phonological anatomy and physiology to aid students in correct production of phonemes.
- Treating congenital and acquired motor speech disorders, using knowledge of neurology, principles of motor planning, and theories of neuroplasticity.
- Ensuring quality of life through functional communication.

PATHOLOGY
- The science of the causes and effects of diseases.
- Reviewing medical records, including imaging, reports, past medical history, previous therapy notes, and physician notes.

LANGUAGE
- The method of human communication, whether spoken or written, consisting of the use of words in a structured and conventional way.
- Synthesizing findings to diagnose, treat, and determine progress on speech sound disorders.
- Synthesizing findings to diagnose, treat, and determine progress on treatment of language disorders.
- Communicating with medical and non-medical professionals including physicians, teachers, social workers, psychologists, physical and occupational therapists, and nurses.

What is SPEECH LANGUAGE PATHOLOGY?

- SPEECH
- LANGUAGE
- PATHOLOGY
Speech-Language Pathology: Targeted Areas

- Speech sounds
- Language
- Literacy
- Social communication
- Voice
- Fluency
- Cognition (cognitive-communication)
- Feeding and swallowing
Speech-Language Pathology: Targeted Areas

- **Speech sounds**
  - Also known as *articulation*
  - How we say sounds and put them together in words and sentences

- **Language**
  - Our ability to express what we are thinking to others, as well as understand what others are expressing to us
    - Can be verbal (speaking) or non-verbal (reading, writing, signing, gestures, facial expressions)
Speech-Language Pathology: Targeted Areas

● **Literacy**
  ○ How well we can read and write
  ○ Issues with language often show up in the form of difficulties with reading, spelling, and writing
    ■ Especially in school-age kids

● **Social communication**
  ○ Also known as *pragmatics*
  ○ How well we understand and follow social rules and expectations
    ■ How close we stand to other people when talking, taking turns when talking, making eye contact to let someone know we’re talking to them, etc.
Speech-Language Pathology: Targeted Areas

● **Voice**
  ○ Sometimes referred to as *phonation*
  ○ How well our voices sound as we speak
  ○ Sometimes people have issues with sounding hoarse, losing their voice, talking too loudly or softly, talking through their nose, or being unable to make sound at all

● **Fluency**
  ○ How well our speech flows
  ○ Stuttering--could be repeating sounds, whole words, or taking a lot of pauses when speaking
  ○ A lot of children go through a phase where they stutter, but many outgrow it
Speech-Language Pathology: Targeted Areas

● **Cognition (cognitive-communication)**
  ○ How well our brains work
  ○ Attention, memory, regulation, problem solving, organization, and more
  ○ Language relies on cognition, and cognition relies on language
    ■ Language is the tool we use when we think

● **Feeding and swallowing**
  ○ How well we can suck, chew, and swallow food and liquid
  ○ Swallowing disorder (dysphagia) is a big area for us
  ○ Can be an issue at any age due to many different reasons
    ■ Prematurity, stroke, TBI, complications from surgery, and more

Speech-Language Pathology: Who does it?

- Speech-Language Pathologists
  - Aka SLPs
- Experts in communication
- Qualification:
  - Master’s degree or higher in Speech-Language Pathology or Communication Sciences and Disorders
    ■ Most have undergraduate degrees in Communication Sciences and Disorders, but not all
  - 400 hours of supervised clinical work in graduate school
  - Passing score on the SLP Praxis Exam
  - 36 week clinical fellowship after graduation
- Completion (of the above) results in the earning of a Certificate of Clinical Competence (CCC)
  - CCC-SLP
Speech-Language Pathology: Who does it?

- **Speech-Language Pathology Assistant**
  - Also known as SLPA
  - Usually have a 2-year associate’s or 4-year bachelor’s degree
  - Must be under the supervision of a certified SLP
    - Can assist with delivering therapy, but cannot perform evaluations

- **Family members**
  - Very important part of therapy!
  - Sometimes clients will be given at-home activities and tasks
  - SLP will train parents, siblings, spouses, etc. on how to work with client on certain skills
  - Increases amount of therapy time per week and can be very beneficial
    - Enhances progress and carry-over of newly learned skills

Speech-Language Pathology Services: Where do they happen?

- Hospitals
- Schools
- Rehabilitation centers
- Skilled nursing facilities/nursing homes
- Colleges and universities
- **Client’s homes**
- Physicians offices
- Private practices
Speech-Language Pathology: Why is it important?

- Speech, language, cognitive, swallowing, and other impairments left untreated are likely to continue throughout school and adulthood
  - Can lead to difficulties with school performance, job performance, job attainment, forming friendships and other relationships
- If impairments are addressed earlier in life (before 5 years old), children tend to have better outcomes later
  - This doesn’t mean that older kids can’t make progress in therapy, but they may make progress at a slower rate because they may have learned and adapted to patterns that need to be changed
Speech-Language Pathology Services within EI

- Work with families and their young children who have (or are at risk of having) 
  delays or disabilities in:
  - Communication, speech, language, cognition, emergent literacy, feeding/swallowing
- Screening/identification
  - Assessments, observations, parent/sibling interviews, etc.
- Prevention
  - Promote healthy development and reduce risk factors that may impact a child’s development
- Help develop intervention programs with team, as well as help with transitions
  - Ex: Transition from home-based services to school-based services
- Collaboration with family, caregivers, other professionals, agencies
- Plan and implement SLP intervention/therapy

Examples of Speech-Language Pathology Services within EI

● Direct Intervention
  ○ Ex: Floortime
    ■ SLP spends 20-30 minutes on the floor playing with the child
    ■ Follows the child’s lead
    ● Look at and work on self-regulation, shared attention, engagement, two-way communication, symbolic play, and more
      ○ Learn the child’s emotional, social, and intellectual differences in motor/sensory/language functioning
Examples of Speech-Language Pathology Services within EI

- Indirect Intervention
  - Ex: Responsivity Education/Prelinguistic Milieu Training
    - Teaching parents to recognize/respond to communication
      - Responsivity
    - Arrange the environment
    - Follow the child’s lead
    - Build social routines
Advocacy Tools
What is advocacy?

- Sharing your story
- Speaking for yourself and for others
- Speaking for our youth!
- Advocating for legislative and system changes
- The goal of self-advocacy is for you to decide what you want then develop and carry out a plan to help you get it
How to be an advocate

- Set goals
- Make an action plan
- Learn about your situation and rights
- Policy
Advocacy for EI

- Low rates of developmental screenings for the United States as a whole
- More restrictive eligibility criteria
- Racial disparities
- EI provided to 3% of population (as of 2015)
- Of those considered eligible: only 10% served
“Zero to Three”

- Advocacy program for individuals and families “to ensure that babies and toddlers benefit from the family and community connections critical to their well-being and development.”
- As an Advocate:
  - Contact Congress about policy
  - Find your Elected Official
  - “Think Baby” campaign:

“Think Baby” Campaign

● Provides data/makeup of state rankings
  ○ Health
  ○ Families
  ○ Early learning experiences

● State policymakers can use this data to see where changes need to be made

<table>
<thead>
<tr>
<th>Early Intervention and Prevention Services</th>
<th></th>
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<tbody>
<tr>
<td>Percentage of infants/toddlers, ages 9 through 35 months, who received a developmental screening using a parent-completed tool in the past year</td>
<td>30.4%</td>
</tr>
<tr>
<td>Percentage of infants/toddlers with moderate/severe developmental delay</td>
<td>1.1%</td>
</tr>
<tr>
<td>Percentage of infants/toddlers receiving the Individuals with Disabilities Education Act Part C services</td>
<td>3.1%</td>
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Parent Training and Information Center (PTI)

- IDEA provides money for state PTIs
  - Free workshops
  - Information regarding specific disabilities and issues
  - Parental and child rights under the law
  - Educational specialists
  - Legal assistance and other resources

The Arc of Illinois
About the Arc of IL

“The Arc of Illinois is committed to empowering persons with disabilities to achieve full participation in community life through informed choices.”

- Office located in Frankfort, IL but The Arc and programs of The Arc serve individuals with disabilities statewide
- Brings together family members, self-advocates, and professionals from many fields through trainings and educational events
- Keeps people up to date on policy and advocacy issues relating to individuals with intellectual and developmental disabilities
- Tons of resources and programs for family members, self-advocates, and professionals to answer questions

The Arc of IL: Programs

- Consumer Stipend Program
- Family Support Network
- Ligas Family Advocates Program
- Illinois Life Span Program
- Family to Family Health Information Center
- Assistive Technology Program
- Etc.

The Arc of IL: Consumer Stipend Program

- Through a grant from the Illinois Council on Developmental Disabilities
- The Arc administers the Consumer Stipend Program and distributes consumer stipend funds to enable people with developmental disabilities and their family members to attend conferences of their choice
  - Directly related to developmental disability issues
- Who Can Apply?
  - Illinois residents
  - A person with a developmental disability
  - Family members of a person with a developmental disability
  - A guardian/foster parent of a person with a developmental disability
- How Much?
  - $400 per person per year
  - $700 per family per year

The Arc of IL: Family Support Network

- Mission is to unite individuals with disabilities and their families to advocate for funding, services, and community resources
- Strengthen and support individuals and the families directly by responding to individual needs and providing empowerment to live in their own homes
- Seeks to ensure the continuation of all individual supports throughout the lifespan
The Arc of IL: Ligas Family Advocates Program

- Ligas vs. Hamos
- In 2005, a lawsuit was filed on behalf of individuals seeking community-based services in Illinois. In June 2011, a judge approved the Ligas Consent Decree, directing Illinois’ Department of Developmental Disabilities to “maintain a fair and accessible process by which individuals with developmental disabilities or their legal guardians can affirmatively request in writing to receive community-based services and/or placement in a community-based setting.” Per the consent decree: “the State will ensure that class individuals with developmental disabilities and their families/guardians are provided information about all options for services.”
- Family Support Network/The Arc Ligas Family Advocates are working with the State of Illinois to ensure that information about all available options for services reaches consumers and their families, according to the requirements of the Consent Decree.
The Arc of IL: Illinois Life Span Program

- Started in 2001
- Website provides information and resources focused on advocacy, services, and supports to individuals with intellectual and/or developmental disabilities, their family members, and anyone who is interested
  - For all ages
- 4 sections: advocacy toolbox, important school and transition resources, website links, calendar of events
- Search tool allows you to look for most requested county or statewide resources
- A toll-free help line is also available during regular business hours so people can call with questions, **1-800-588-7002**
The Arc of IL: Illinois Life Span Program

- Monthly Webinars--Generally second Tuesday of each month, cover a variety of topics of interest. Archived on The Arc of IL website.

- Advocacy toolbox
  - 13 categories
    - Special education services, transition, adult services, advocacy groups, etc.

- Important school and transition resources
  - Transition checklist for teens, work placement, health insurance, tips/guidelines from parents, etc.

- Website links
  - Camps, day care, emergency preparedness, toy resources, transportation resources, etc.

- Calendar of events
  - Events throughout Illinois
    - Conferences, webinars, focus groups, etc.

The Arc of IL: Family to Family Health Information Center

- Free service for families of children and youth with special health care needs, funded by the U.S. Health Resources and Services Administration (HRSA) and The Arc of Illinois
- They offer:
  - Information and referral
  - Health-related training opportunities for families, youth, and professional helpers (providers)
  - Specialized training for parent leaders and organizations
  - Linkages to local, regional, statewide, and national partners
- Information available via the website, phone, or email
  - **Phone:** 815-464-8247
    **Toll Free:** 866-931-1110
  - familytofamily@thearcofil.org

The Arc of IL. F2F Retrieved from https://www.familyvoicesillinois.org/
The Arc of IL: Assistive Technology Program

- Can be used to help fund the purchase of assistive technology for individuals with intellectual and/or developmental disabilities
  - Must have received an evaluation/assessment from a qualified provider
- Can be used when this purchase isn’t supported financially by Medicaid, Medicare, or Private Insurance
- Technology that can facilitate and help with education, employment, community living, and independence
  - Primarily iPads, but other technology has been purchased in the past
- 100% of these funds are received from donors to the Assistive Technology Program, which can be donated to online

The Arc of IL: Assistive Technology Program

- **Who can apply?**
  - Someone with an intellectual and/or developmental disability
  - A family member on behalf of someone with an intellectual and/or developmental disability
  - Illinois residents only

- **Maximum amount is $500 per person/family**

- **Applications can be completed online or mailed to the Arc of IL**
  - Provide some basic information regarding the prospective device user, provide information regarding services currently being received, provide reasoning for need for device, attach a copy of the professional evaluation/assessment that shows the need for the specific assistive technology device
The Arc of IL: Trainings

UPCOMING EVENTS

Upcoming Events

* Previous Events

April 2019

Illinois Life Span Program of The Arc of IL Lunchtime
With a Special Needs Advocate

MAIN MENU

- 2018 Arc Legislative Platform
- Assistive Technology Program
- Applying For Services & Puts

The Arc of IL. Retrieved from https://www.thearcofil.org/events
Thanks!

Contact us:
Anna_R_Hastings@rush.edu
Mary_Connelly@rush.edu

https://www.thearcofil.org/
https://www.illinoislend.org/
References


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References


Questions?