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**

- <u>Leadership Education in Neurodevelopmental and Related Disabilities</u>
- 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 <u>for</u> and <u>with</u> 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
  - o 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 El
- 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
  - o (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

Child's Norm: Cecilifa Johnson  SECTION 3: FUNCTIONAL OUTCOME # May be used as an Annual goal statement for Part 8 Pm	Indiv	lop one outcome per idually. Each outcor	5-2340-5953-00bate: 9-23-06 page. Assign outcome # to identify each page me may have several services, strategles and/or activities achievement of the outcome.
	The state of the s	to sits	afely by herself
What do we want for <u>Cecilia</u> a  Cecilia will sit safe	and our family? (What does the fam.	illy want and why?) that she	ean play without falling.
How will via achieve this outcome? (List strategies and/or activities designed to facilitate the achievement of this outcome and/or stape to the stake to this us to services and/or secure funding for services if not required to be provided by the Part C Early Intervention System)	What Early intervention and/or other services and supports would help us with this?	Fund Source	Upon review, how are we doing? Has our outcome been achieved? Should our outcome, strategies, softwittes and/or services change? If so, how? William parental convent required to change any services.
-Model techniques to encourage cecilia to soend time on her belly -Demonstrate techniques for Cecilia to move the and out of pla certain positions during floor play identify motivating toys to encourage her explanation	Family Service coordinato Physical Thrapis		
8			89
	ns. To the extent appropriate, services needed to achieve this	fices must be provid a outcome being pro	he context of the family, their home, their community, ed in the types of settings in which young children without wided in natural environments?No
Note regarding Fund Source: All Part C Early Intervention Services Source (i.e. Wedcald, ORCC, private resource) which is effor respon- II. 444-4259 (R-06-07) Pages 4 of 11	must be pre-authorized. For all other services iden native for payment or from which payment is being SECTION 3.	g wought.	wited to be provided by the Part C Early Intervention System, include the fuero

#### The Early Intervention / IFSP Process

Service Delivery Identification Intake and Family **Child Evaluation IFSP Development** and Transition and Referral Assessment and Assessment 45 Days Service Coordinator schedules Initial Visit El program receives Service Coordinator requests existing Service Coordinator provides Service Coordinator family with prior notice for initial with family (confirms in writing); developmental and medical information. ensures that service referral, collects IFSP Meeting and prepares determines need to conduct screening. providers implement information on referral family for meeting. timely IFSP services. source's reason(s) for Service Coordinator: referral and results of Service coordinator acknowledges referral Determines if child automatically screening or assessment. Service Coordinator IFSP team meets to develop in writing with referral source. eligible (diagnosed condition); IFSP including: coordinates ongoing Determines necessary evaluation and Reviewing parents' priorities service provision and assessment to identify child's Service Coordinator and concerns: ensures timely IFSP Service Coordinator meets with family and: developmental status and unique assigned. Child record Establishing functional / reviews and annual IFSP o Conducts screening if appropriate; needs in each developmental area: established. measurable outcomes: meeting to modify IFSP. Explains program; Determines composition of evaluation Identifying strategies; o Determines with family if they wish to and assessment team: o Identifying necessary Schedules evaluation and assessment Service Coordinator have child evaluated and assessed. services and timelines for with team and family at place and time Service Coordinator: contacts family to gather initiating services. convenient with family: Provides prior written family's concerns and notice / rights) and Provides written prior notice; and NO YES general information about Provides and explains rights. coordinates timely Service coordinator obtains child, provide information transition conference; parents consent for IFSP about program, and Coordinates developina Service coordinator: services (signing IFSP). determine family's interest Service Coordinator prepares family transition plan: o Provides and explains rights; in scheduling Initial visit. and coordinates team preparation for o Ensures LEA notification: o Obtains written parent consent for Obtains consent for evaluation and assessment. **Consent NOT** evaluation and assessment of child and Consent release of information to provided for provided request/release of information forms; appropriate entity; some or all. for all. o Provides prior notice for evaluation. YES o Ensures implementation of NO Team, including family, conducts evaluation and assessment, determines transition plan to ensure smooth transition eligibility, and provides prior notice and Implement services for which Service coordinator: rights based on eligibility decision. Service Coordinator: o Gathers information about child; consent was provided. For Sends letter to parent those services that consent is o Discusses everyday routines and Service Coordinator: documenting decision and not provided, service coordinator activities of child and family. If NOT eligible, service o Provides transition outlining how to re-contact provides and explains parental coordinator links with o Identifies parental concerns and eliaible program if future concerns; rights (including information on follow-up: appropriate community priorities for their child and family; o With parental consent complaints / mediation process): o Provides prior resources and how to reo Identifies family resources to assist in communicates with referral provides prior notice to not notice/rights to contact program if addressing priorities and concerns. source regarding parent's provide these services and how discontinue services: concerns in future. decision. to re-contact program in future. Closes child record.

#### Types of services that may be included in El:

- 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?

Providing auditory training for individuals with hearing loss or auditory processing disorders

Using knowledge of oropharyngeal anatomy and physiology to aid students in correct production of phonemes

Providing multi-faceted therapy for individuals with congenital or acquired fluency disorders

express thoughts and feelings by articulate sounds

Treating congenital and acquired motor speech disorders, using knowledge of neurology, principles of motor planning and theories on neuroplasticity

Providing evidenced-based intervention for voice and resonance disorders, including behavioral interventions and pharyngeal strengthening exercises

Integrating knowledge of oropharyngeal anatomy and physiology to diagnose and treat swallowing disorders

Utilizing extensive knowledge in neurology, and oropharyngeal anatomy and physiology to make appropriate diagnoses and referrals

Synthesizing

Ensuring quality of life through functional communication!

to determine

prior level of

function or

developmental

history

findings to diagnose treat, and determine progress on treatment for speech sound disorders Interviewing family members

> Communicating with medical and non-medical professionals including physicians, teachers, social workers, psychologists, physical and occupational therapists, and nurses

> > Taking inventory of symptoms and comorbid conditions to determine diagnosis and evidenced-base treatment options

Addressing disorders of the phonological system, including those that impact speech production, language development. and literacy

Programming and training use of low-tech and high-tech augmentative and alternative communication. including sign language

Instruction in all aspects of written, oral, and augmentative language. including the comprehension and use of vocabulary, syntax, grammar, written language, phonological processing, nonverbal communication sign language, and social language

spoken or written, consisting of the use of words in a structured and conventional way.

> Training communicative partners to support individuals with complex communication needs

> > Treating and diagnosing cognitive communication disorders, including disorders of executive function, verbal problem solving, language memory, and attention.

the science of the causes and effects of diseases

Reviewing medical records, including imaging, reports, past medical history, previous therapy notes, and physician

Latta Speech & Language Services www.lattaspeechandlanguageservices.com

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

#### 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)

#### Literacy

- How well we can read and write
- o 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.

#### 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

#### 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
  - O 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
  - O 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 El

- Work with families and their young children who have (or are at risk of having)
   delays or disabilities in:
  - o 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
  - o 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 El

- 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 El

- 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

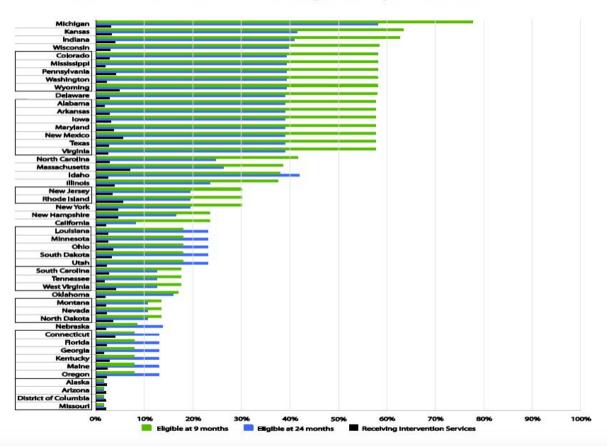


#### Advocacy for El

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



#### **Estimated Rates of Eligibility for Part C**



#### "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:



Zero to Three. (2017). Think Babies: Make their potential our priority. Retrieved from https://www.youtube.com/watch?time\_continue=82&v=RBcltw\_DFKs.

#### "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

Early Inter-	Percentage of infants/toddlers, ages 9 through 35 months, who received a developmental screening using a parent-completed tool in the past year	30.4%
vention and Prevention Services	Percentage of infants/toddlers with moderate/ severe developmental delay	1.1%
Jei vices	Percentage of infants/toddlers receiving the Individuals with Disabilities Education Act Part C services	3.1%

#### 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
  - o 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
  - o 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

o **Phone:** 815-464-8247

**Toll Free:** 866-931-1110

familytofamily@thearcofil.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



		Date Date	VIEW AS :≡ List
Previous Events			
	April 2019		



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

#### Thanks!

Contact us:

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





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# Questions?

