

Illinois Department of Human Services Early Intervention Service System (EISS) Guidelines for Occupational Therapy, Physical Therapy, Speech Therapy, and Developmental Therapy

Overview

In an effort to assure that children 0-3 with developmental delays and their families receive the services and support they need to address their developmental needs, the Department of Human Services (DHS) convened a Special Advisory Panel to develop guidelines for Physical Therapy (PT), Occupational Therapy (OT), Speech Therapy (ST), and Developmental Therapy (DT) services through the Illinois Early Intervention (EI) Program. This panel, comprised of families, medical providers, therapists, and advocacy organizations, helped to develop this document. DHS gratefully acknowledges their assistance in this process. Members of the Special Advisory Panel are listed in Appendix C.

To ensure that all eligible children and their families receive appropriate and quality interventions, a quality enhancement process has been developed for the EISS. DHS will use the guidelines as one component of the quality enhancement process; the additional sections of the document will be used for training. These guidelines are not fixed protocols; they merely indicate typical courses of intervention. There may be children who may benefit from more or less intervention, justified by documentation of special circumstances. Intervention must be based upon a child's need and professional judgment. Guidelines are not entirely inclusive or exclusive of all methods of reasonable intervention which can obtain the same results, or which consider the particular needs of the child and available resources. These guidelines are a work in progress, and will be reviewed and refined as experience is gained from the quality enhancement process.

Vision

The Special Advisory Panel was convened to assist DHS develop a standard of practice that serves the needs of Illinois' infants, toddlers and their families, reflects accepted knowledge of child development and current best intervention practice, and that is based on the central, fundamental role of the family.

The Illinois EI Program is based on a collaborative and equal relationship between families and providers that affirms and supports the family's role as a member of the team. The Individual Family Service Plan (IFSP) will be a plan that addresses the priorities, resources, and concerns of the family and child to address the child's development. Services should be individualized for the child and family, and designed to enhance the family's ability to promote their child's development within the context of the family and community.

Decisions regarding services will be made by consensus of the team. The team includes the parents or guardian, providers, and service coordinator. The IFSP will be a "living document" of that consensus, the objective evidence of a process that includes the family.

Consensus is achieved through collaborative decision-making. Both families and providers are active participants in developing the IFSP. Communication is two-way. Family knowledge and provider knowledge determines intervention outcomes, services, and strategies. Providers do not dictate to families what they or their child need; nor do families solely determine the service plan content. Because EI relies on families to embed intervention strategies into their family routines, in the end, service planning decisions must be those that work for the family. Parental choice regarding intervention goals is a recognized standard for best

practice assuring successful results in family-centered services. To help ensure that intervention recommendations are “doable” by families, interventions should be meaningful in terms of family culture, beliefs and values, congruent with child characteristics and needs, and sustainable over time, given family priorities and resources.

A primary goal of EI is to enable families to interact comfortably with their child and to support families in promoting their child’s development. The parent-child relationship is first and foremost an emotional bond. Therefore, all intervention activities should support parental acceptance, nurturance, and emotional attunement to the child. Child intervention suggestions are best designed with the family, building on the ways that parents, family and child naturally interact. Interventions, whether by their nature or intensity, which overstress the parent/child relationship or place excessive demands on families will not, in the end, help parents promote their child’s development. Parent education approaches based on family-identified need and mutual exchange will be most effective in building the family’s capacity to understand and meet their child’s special needs. Approaches that are overly didactic or imposed on families will be counterproductive.

The majority of children in the EI program do not have, and are not likely to have, a medical diagnosis or clear cause for delay. Many children, therefore, will not usually require or benefit from direct OT, PT, or ST. Other interventions and supports are available through the EISS (including the other 12 services) and through other federal, state, and community programs. All of these options should be addressed during the IFSP discussions to help the family understand the array of services which may be available to them.

Although an extensive array of professional services is available through the EI Program, it is the parents who provide the real early intervention by creatively adapting their child care methods to facilitate the development of their child. Consequently, all intervention strategies should include an educational focus that facilitates social interaction, curiosity, exploration, learning, and autonomy. To maximize the child’s development, all intervention goals should be integrated into a coherent plan built around family routines and activities of interest and meaning to the child.

Quality services demonstrate respect for family diversity. Families will differ in their level and type of involvement in EI. Families change over time and may seek more intense involvement at certain periods and less intense involvement at other times. Service plans should be variable, reflecting family diversity and changing needs of the child. Families should participate at every stage of IFSP development. Any revision of the IFSP requires prior review by the team and parental notification, and must include clearly stated outcomes.

The quality enhancement process will use concrete measures to ensure that the IFSP reflects this vision. The following guidelines will be used to assure that IFSPs are family-centered.

1. The service plan clearly links the intervention plan to identified child and family needs.
2. All communication related to the service plan is presented in the family’s primary language.
3. There is documented evidence that the family participated in the development of the IFSP including signed consent for the plan and proposed services.
4. Expectations for outcomes and timelines are identified.

5. The service coordinator provides information on how to access all recommended services.
6. Families are identified and supported as the primary providers for their child.
7. All information related to a child's behavior, development and intervention strategies (including evaluation and assessment reports) will be available to families.
8. Service plans should reflect all the services needed by the child and family which promote the child's development, including other providers and funding sources. Efforts are made to coordinate services.
9. All members of the team sign the final service plan.

Utilization of Developmental Therapy, Occupational Therapy, Physical Therapy, and Speech Therapy

The focus of these guidelines is to help EI team members (evaluators, educators, therapists, service coordinators, parents) and reviewers decide the most appropriate constellation of therapeutic intervention services for a child who is eligible for EI services. Specifically, these guidelines will provide a clinical reasoning process to determine when OT, PT, ST, and DT are appropriate and frequencies for each therapy. This clinical reasoning process is based on clinical research (when available) and on expert clinical opinion from representatives of the different disciplines who work with child development where research is not available.

Children are considered eligible for EI when they are diagnosed with an eligible medical condition or when their development is substantially delayed. Children with developmental delays will usually follow one of three patterns:

- (1) typical, with global delay (**typical/global**);
- (2) typical with uneven severity of the delay (**typical/variable**); or
- (3) **atypical**.

For children with typical delays, their development would be considered "age appropriate" for a younger child. A child with global delay has delays that are equal in all domains, in contrast to the child with a delay in one or more area that is more severe than the others. An example of the typical/global would be an 18 month old child whose motor, cognitive, language, adaptive, and social skills are all at the 9 month level. An example of the typical/variable would be an 18 month old child whose motor, cognitive, social, and adaptive skills are at 12 months, while language skills are at 6 months. These two scenarios are considerably different from the child whose developmental is not only delayed, but "atypical" or different in quality at any age. Example of atypical development would include toe walking, scissoring of the legs during ambulation, a persistent clenched fist, echolalia (obsessive repetition of sounds, words, or phrases), or avoidance of eye contact. The constellation of therapeutic services will be different for each of these children.

Evaluation/Assessment

The primary goal of the evaluation/assessment is to address parents' questions and concerns about their child's development and to identify ways families can participate in the child's intervention program.

Evaluation/assessment of each developmental domain including a multi-disciplinary team discussion is imperative to understand the child's strengths and needs.

EI services should be based on a collaborative relationship between families and providers that emphasizes the family's role as central in EI activities. The evaluation/assessment process should begin with an exploration of the family's specific developmental concerns and their functional goals. The family's concerns coupled with the findings on a global assessment will determine the specific developmental areas that are in question, and the need for additional evaluations/assessments in those areas. These evaluations/assessments can then be used to develop family-centered functional goals and specific intervention strategies.

Evaluation/assessment includes professional observation and interpretation of the quality of a child's performance of developmental tasks and how these are integrated into the daily routines of the family. This requires full family participation throughout the assessment process to ensure that the therapists' observations are a meaningful reflection of the family's perspective. A list of recommended assessment tools is found in Appendix B. This list does not preclude the use of other research-based, valid tools for assessment of infants and toddlers.

Following the evaluation/assessment, an IFSP is optimally developed with all of the team members present and to provide input. The IFSP must be reviewed every six months to evaluate the child's progress in meeting the established goals. During this process, it is determined which services and interventions are warranted, and the expected outcomes as well as the frequency of those interventions, based upon the guidelines in Appendix A.

Considerations for Therapies in Meeting the Child and Family's Developmental Needs

EI attempts to achieve goals and outcomes which are important to the family's routines and priorities for the development of their child. The family is the primary foundation of their child's optimal development in all areas. In order for therapy to be successful, it is essential for families to be involved in facilitating carryover to daily living activities. This means that an important goal of therapist-family collaboration is to support the child's participation in the family and their functional environment. It is advisable to provide families with written instructions for home activity to amplify and support therapeutic goals. Frequency of therapy should depend on the amount of time necessary for the family to incorporate new techniques into family routines and reevaluation/assessment of the child's response to therapy. If the only time the child is performing functionally relevant therapeutic activities is during the session with the therapist, therapy is not likely to be beneficial and therefore not supported by Part C. To extend that premise, if the child is making progress at a rate that requires the therapist to vary the treatment and the home program monthly, multiple weekly visits are not appropriate.

Intervention services should be considered as a means of achieving the functional goals that have been determined by the IFSP development team. Specific strategies should be collaborative and interdisciplinary, avoiding unnecessary duplication of similar activities by multiple therapists. For example an occupational therapist can provide specific recommendations for upper extremity activities to the physical therapist that can be incorporated into a single, comprehensive motor plan. In some circumstances, both therapies are needed to address specific goals. Motor intervention with young children, however, often involves non-specific motor strategies that are used by both disciplines.

The inclusion of specific therapies in the intervention plan should never be based solely on the presence of a medical diagnosis or delay. For example, all children with cerebral palsy do not need PT just because they have cerebral palsy, and all children with language delays do not need ST just because they have a language delay. Therapy should be linked to specific goals and outcomes, regardless of the underlying cause.

Deciding whether a child will benefit from therapy depends on many factors including his overall developmental status and specific functional deficits. Many children eligible for EI are typically delayed, do not have an identifiable reason for their impairments, and will not usually require direct OT, PT, or ST. Choosing an intervention strategy for a child and family requires as complete an understanding as possible of the reasons for delay or impairment, its likely natural history, the child's personality and health, and the family's point of view. It is also important to remember that therapy can be provided in several different service delivery models, not just once or twice a week. There are many children who require therapeutic contact, but only at periodic intervals. The various service delivery models are described below. Finally, the importance of involving families in the therapeutic process by integrating therapeutic activities into daily routines needs to be considered. In general, a need for therapy depends on the answers to several questions.

- Is a particular skill, e.g., walking, delayed more than the child's general overall development (typical/variable)? If no, therapy is probably not indicated. If yes, can we discern why (vision, hearing, poor endurance due to health problems, lack of movement, lack of strength, sensory problems, lack of opportunity to practice)? The answer to that "why" will tell us whether direct therapy may be helpful (e.g. to strengthen, to adapt the task) or not. Is the answer to that question logical in terms of the medical diagnosis? If so, is direct therapy usually helpful? If a medical diagnosis has not been determined, does the child need a medical diagnostic evaluation?
- Are the prerequisites for that skill emerging or present? If so, are they typical? For example, a child is not walking but can assume sitting and coming to stand; a child is not chewing but is munching and lateralizing the tongue. Direct therapy is likely not needed. If the prerequisite skills are not emerging, do we know why (vision, hearing, endurance, sensory problems, weakness, lack of opportunity to practice)? Can these areas be improved medically, by family education, or environmental change? Direct therapy may be helpful here. Is the major limitation lack of practice or lack of endurance? If so, therapeutic consultation and development of a program to be carried out by educators and parents may be more appropriate.
- Is the reason for the lack of emergence of a skill potentially remediable? If it is, then the focus should be on that remediation (strengthening, medical management of seizures, provision of eye glasses). Much of specific remediation is medical and outside the realm of EI services. If, however, the reason for lack of development of a functionally important skill is remediable, e.g.: lack of strength of an innervated muscle, then direct therapy is likely to be helpful. If not, therapy should be focused on a different means of establishing the function. For example, the focus of PT in a child with spina bifida is not to make the legs strong but to promote the trunk, upper extremity, balance and motor planning skills necessary for adapted ambulation and wheelchair use. The focus of OT in a child with pervasive developmental disorder is to help the child tolerate and learn from sensory stimuli and therefore to be able to tolerate sensorimotor and social exploration, not to "normalize behavior." If a child is not talking because he is profoundly hearing impaired, the focus of therapy will be on multi-modal communication. If the reason for lack of development of a functionally important skill is remediable, e.g. lack of strength of an innervated muscle, then therapy is likely to be helpful.

In general, for a child to benefit from direct therapy (OT, PT, and ST), in addition to developmental intervention, the following should be considered:

- A child whose development is typical and globally delayed (typical/global) will probably not need extensive PT, OT, ST services. The functional goals for a child with global developmental delays can usually be met with a home activity program and periodic monitoring and/or consultation.
- A child whose development is delayed with specific areas out of proportion from overall development (an uneven severity of the delay – typical/variable – will likely benefit from direct therapy in the domains of greater delay.
- A child with atypical development will generally benefit from direct therapy in the atypical domain.
- A child with a specific medical diagnosis will probably benefit from direct therapy, although the provision of services should be based on functional deficits and functional goals, and not only on the presence of a diagnosis.
- A child who has delays based solely on a lack of experience or “immaturity” will probably benefit more from DT than from other direct therapy services.
- A child for whom any adaptation to a task or for whom adaptive equipment is being considered will probably benefit from direct or consultative OT, PT, or ST.
- Direct therapy should be based on family-centered function goals. OT, PT, or ST is probably not indicated when the only goal is nonspecific developmental progress or “age-appropriate” development.
- Improved endurance or improved speed in completing a task is an appropriate goal for direct OT, PT, or ST only if the lack of speed or endurance results in a functional delay.

Models of Therapy Services

In *direct service* the therapist provides one-on-one interaction with the child and family or with a small group of children. Direct service is appropriate when specialized approaches and techniques are needed that are individualized to the child and require the skills of a trained therapist to administer. In virtually all areas of therapy, direct service consists of various components, including 1) educational (teaching, demonstrating, promoting the use of a skill which the child has the understanding and physical capacity to perform but is not doing so consistently); 2) remediation or work on improving the child’s capacity to do a component of the skill through use of therapeutic techniques (e.g., stretching to improve range of motion, massage to free up joints, changing the environment, providing a sensory stimulus); 3) expert alteration of the task (provision of adaptive equipment for mobility or self feeding), and 4) co-treatment. All of the treatment modalities depend on the therapists’ expert understanding of the foundations of the task, of ongoing observation of the response to the treatment, and to varying the treatment depending on the response of the child.

Monitoring of the intervention services involves evaluating/assessing the child, development of a program and teaching family members and other team members to implement the program. Monitoring occurs when the frequency of therapy is determined to be monthly or less. The therapist remains responsible for the

outcome of the plan and oversees the program to ensure that the procedures are implemented on a consistent basis. Monitoring also involves a focused reevaluation of a child to see if the child is meeting goals as written on the service plan, given his overall health, sensorimotor and developmental status and requires provision by an EI professional. Implicit in the idea of monitoring is that if expected progress is not occurring, or regression is occurring, the process will change in some way. This may include reevaluation/assessment, revision of the service plan or referral for medical diagnostic evaluation.

Consultation involves the request of one professional to another regarding a specific area of concern. The consultation may require several contacts, but ends with a response and recommendations. Consultation consists of an evaluation by a therapist with subsequent direction to the child's parents, educators or other professionals, regarding activities or program modifications which can be incorporated into play, self care, and/or educational routines. Consultative services are designed to enable others to meet their expressed goals and may or may not involve hands-on work by the therapist with the child. In consultation the therapist uses their knowledge and experience to enable another person to interact with the child or group of children more successfully. Consultation may include directions for positioning, suggesting activities that promote the acquisition of certain functional skills, modifications to an existing program to improve endurance and speed, recommendations for orthotics, and making suggestions for environmental changes.

Often monitoring or consultative services could be done in a co-treatment model.

Service Guideline Parameters

Children and their families enter the EISS because of concerns about one or more aspects of the child's development, or because they are known to have conditions likely to result in impairment of the quality and rate of development. Children and families receive services intended to improve function, promote social competence and integration, enable families to understand their children's needs and address them, and prevent secondary disabilities. The areas targeted for intervention and the methods of intervention are reflected in an IFSP.

It is understood within the context of these guidelines for provision of therapy that:

- § EI services are based on measurable goals that are reviewed with the family every six months through the IFSP process. The age and/or developmental level may impact the frequency of service. The eligibility will be reviewed annually.
- § All intervention strategies should include a developmental focus that facilitates social interaction, curiosity, exploration, and learning.

The guidelines which follow are an attempt to provide guidance for professionals working with children who have an identified medical diagnoses and/or developmental delays. The specific diagnoses are not all inclusive but they are high-severity diagnoses and relatively common within the EI population. The lack of a specific diagnosis or the presence of less prevalent diagnoses does not deny access to developmentally indicated therapy.

It is explicitly understood that medically prescribed therapy may need to be more intense than what is provided within the EISS. Individual children, families, therapists, and physicians may also request and provide services of different types and different intensity outside the EI system.

Some children have sustained acute injuries that have resulted in developmental delays. Acute rehabilitative therapy is not an educationally or developmentally based process, and should remain a medically based service outside the EI arena. Once the condition has become subacute or chronic, as determined by the child's physician, the therapy treating the developmental delay can and should be provided by the EISS.

Some children may have multiple delays, and will therefore require a higher frequency of services. It is anticipated that such services may be supported by other programs which provide medical therapies. All intervention services including assessments within the EI system must be provided according to Illinois law. Some services require a prescription. The prescription must include a diagnosis (if there is one), and any precautions, and should include at least three short-term goals to be addressed over the succeeding six months. An evaluation/assessment of the child's status must be obtained prior to the initiation of therapy, and objective change must be documented at least once every six months to determine the child's progress. Examples of objective testing include the Peabody, GMFM, manual muscle testing, range of motion, SICD, etc. A list of acceptable assessment tools is included in Appendix B. Goals can include maintenance of current function or prevention of loss of function, if appropriate. The initial status and the rate of progress must be included in the IFSP.

These guidelines only apply to DT, ST, OT, and PT. There are no clear, universally accepted guidelines that identify a specific frequency of any therapy that is most appropriate for all children with developmental delays and specific disabling conditions. The EISS offers 12 additional services which address a child's developmental delay; these services as well as other programs/supports should be considered and offered to the family. All conditions, including developmental delay, may affect the way the child is integrated into the family. The following guidelines provide a range and total cumulative hours which would apply for most children in need of EI services. With appropriate clinical justification, exceptions to these guidelines may be appropriate. Justification needs to answer the following questions:

- C What specific results are expected that warrant an increased amount of service?
- C What are the specific factors about this child that lead the team to determine more/less services are needed?
- C Is the child eligible to receive these therapy services from other programs (e.g., DSCC, Prevention Initiative programs, Early Head Start); why aren't these resources responsible for providing these services?

In cases where specific areas are impaired, the minimum frequency is usually one time per month in that area. Some children will present with multiple impairments. In this case, the number of therapy sessions is not additive, but is driven by the developmental needs of the child. Total cumulative therapy sessions are not a sum of hours of service, but rather represent optimal interventions when provided in an integrated, multidisciplinary developmental model. No service should be considered "mandatory," but DT should be considered for most children.

1. **Cerebral Palsy.** Cerebral Palsy is a condition which affects motor function; children may have other impairments as well. Therefore, OT and PT should be part of the IFSP; generally a frequency of OT and PT less than monthly or more than once weekly should be reviewed. The usual frequency of ST is evaluation once to twice weekly. The usual frequency for DT is once monthly to twice weekly. Most children with Cerebral Palsy will require 12 or less combined total therapy sessions monthly. A total of more than 12 combined total therapy sessions monthly will require further justification.

2. **Spina Bifida.** Spina Bifida is a condition which affects motor function; children often have other impairments. Therefore, OT and PT should be part of the IFSP. Generally, quantities of PT are monthly to twice weekly. The usual frequency of OT may range from once monthly to once weekly. The usual frequency for DT is once monthly to once weekly. Precautions of insensate skin and osteoporosis are presumed with this diagnosis. Most children with Spina Bifida will require 8 or less combined total therapy sessions monthly. A total of more than 8 combined total therapy sessions monthly will require further justification.
3. **Down Syndrome.** Down Syndrome is a condition which usually affects cognition. Not all children with Down Syndrome require specific OT and PT. All children with Down Syndrome will benefit from a PT evaluation to develop a home program for positioning and handling because of the underlying hypotonia. Acceptable frequency of PT is from an evaluation once every three months to once weekly therapy. Activities involving cervical flexion/extension are contraindicated. OT to foster self-care skills and exploratory play is often helpful. The usual range is from evaluation every three months to once weekly therapy. Feeding evaluation and ongoing feeding therapy weekly is appropriate for children who have oral motor/feeding dysfunction. Communication/Speech-Language evaluation for children with Down Syndrome may be appropriate; the usual frequency is from evaluation once every three months to once weekly. The usual frequency for DT is once monthly to once weekly. Most children with Down Syndrome will require 6 or less combined total therapy sessions monthly. A total of more than 6 combined total therapy sessions monthly will require further justification.
4. **Pervasive Developmental Disorder (PDD).** PDD is predominantly a condition of impaired communication and social development. Communication therapy is always indicated for children with this problem, with a usual range of weekly to twice weekly. OT is usually indicated to facilitate self-regulatory skills necessary for participation in all the child's environments and to promote self-care and play skills with a usual frequency of monthly to twice weekly. PT is rarely indicated. DT is always indicated with the usual frequency of 2-4 times weekly. This is an area where expert opinion is rapidly evolving. Most children with PDD will require 16 or less combined total therapy sessions monthly. More than 16 combined total therapy sessions monthly will require further justification.
- 5.-8. **Children With a Developmental Delay and/or Other Medical Diagnosis.** Therapy services when authorized for specific goals may have an appropriate frequency ranging from evaluation/assessment only to direct services no more than four times monthly, including ST, OT, and PT. Consultative services by therapists to parents and educators may have an appropriate frequency of evaluation/assessment only to once monthly each for ST, OT, and PT.

As discussed extensively above, therapy must be goal directed, must include family education, must be associated with progress toward goals when reviewed at mandated times, and must be used for goals which are appropriate for the child's overall functional status.

Severity of disability does not, by itself, justify increased amounts of therapy. Prevention of secondary disability, e.g. contractures and tolerance of movement, sensory stimulation, and social stimulation are appropriate goals for young and/or severely affected infants but can usually be accomplished with consultative or intermittent direct therapy.

Most children who are delayed and/or have another medical diagnosis but who are typically developing will require 5 or less combined therapy sessions monthly. A total of more than 5 combined total

therapy sessions monthly will require further justification for those children who are delayed but typically developing. A total of more than 8 combined total therapy sessions monthly will require further justification for those children who are delayed and/or have another medical diagnosis and demonstrate atypical development.

9. **Typical/Variable: Speech-language Delay.** Children whose presenting concern is delayed receptive language, expressive language and/or articulation. These children need evaluation/assessment of hearing and other areas of their development. ST is indicated with a usual frequency of monthly to twice weekly. The usual frequency for DT is once to twice weekly. Most children with speech language delay will require 8 or less combined total therapy sessions monthly. A total of more than 8 combined total therapy sessions monthly will require further justification.
10. **Typical/Variable: Hearing Impairment.** Speech-language aural rehabilitation therapy is always indicated. Family education regarding treatment and education options should always be a part of the IFSP. The usual frequency of ST would be once to twice weekly. The usual frequency for DT is once monthly to once weekly. Most children with hearing impairment will require 12 or less combined total therapy sessions monthly. More than 12 combined total therapy sessions will require further justification.
11. **Typical/Variable: Vision Impairment.** Children with visual impairment who are not profoundly developmentally impaired require OT for self-care skills, environmental exploration and to learn adaptive mobility techniques. The usual frequency is monthly to twice weekly. PT is often indicated for mobility impairments. The usual frequency is monthly to weekly. Communication impairments are common; severely visually impaired children should undergo a speech-language evaluation by one year of age. The usual frequency for DT is once monthly to twice weekly. Most children with vision impairment will require 12 or less combined total therapy sessions monthly. More than 12 total combined therapy sessions monthly will require further justification.
12. **Typical/Variable: Unspecified.** These children will require services to address the area of variable developmental delay. This may include OT, PT, ST, and/or DT. The usual frequency will depend upon the level of delay. Most children will require 5 or less combined total therapy sessions monthly. A total of more than 5 combined total therapy sessions will require further justification.