

RCPA Early Intervention Steering Committee Position Paper: Early Intervention Eligibility in Pennsylvania

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INTRODUCTION

Pennsylvania's early intervention (EI) system is designed as a family and caregiver coaching support model providing services to families with children who have developmental delays or disabilities. Early intervention services build upon the natural learning opportunities that occur within the daily routines of a child and their family. By intervening early, interventionists help the child, family, and caregivers learn essential skills and education to promote timely, healthy development.

Domains of development are interrelated and experiences during early childhood impact a child's development over their lifespan. Early identification, assessment, and intervention to address concerns are essential. As such, it is important that *all* children who demonstrate delays or who present with established risk factors known to impact development be identified and served. To promote access to services, it is imperative that eligibility practices across the commonwealth are consistent to ensure equitable access for all.

CURRENT REGULATIONS

In order to determine eligibility for early intervention services, a thorough assessment and evaluation are completed. If a child meets eligibility criteria, the early intervention team will recommend appropriate services to address the identified needs of the child and family. Title 55, Chapter 4226 of the Pennsylvania Code clearly outlines the criteria for eligibility for (Part C) early intervention services.

From §4226.22, the county MH/MR program shall ensure that early intervention services are provided to all children who meet one or more of the following criteria:

- (1) A developmental delay, as measured by appropriate diagnostic instruments and procedures, of 25% of the child's chronological age in one or more of the developmental areas of cognitive development; physical development, including vision and hearing; communication development; social or emotional development; and adaptive development.
- (2) A developmental delay in one or more of the developmental areas of cognitive development; physical development, including vision and hearing; communication development; social or emotional development; and adaptive development, as documented by test performance of 1.5 standard deviations below the mean on accepted or recognized standard tests for infants and toddlers.
- (3) A diagnosed physical or mental condition which has a high probability of resulting in a developmental delay as specified in paragraphs (1) and (2), including a physical or mental condition identified through an MDE, conducted in accordance with § 4226.61 (relating to MDE), that is not accompanied by delays in a developmental area at the time of diagnosis.
- (b) In addition to the diagnostic tools and standard tests specified in subsection (a)(1) and (2), informed clinical opinion shall be used to establish eligibility, especially when there are no standardized measures or the standardized measures are not appropriate for a child's chronological age or developmental area. Informed clinical opinion makes use of qualitative and quantitative information to assist in forming a determination

regarding difficult-to-measure aspects of current developmental status and the potential need for early intervention.

The Pennsylvania code outlines four clear pathways (eligibility criteria) by which families in Pennsylvania may access early intervention services for a child under three years of age. All of these eligibility pathways (developmental delay measured by 25% of the child's chronological age OR 1.5 standard deviations below the mean OR a diagnosis with a high probability of resulting in a developmental delay OR informed clinical opinion) are equally emphasized in Title 55, with no one path deemed preferable or inferior. Equal, informed use of each pathway affords families in Pennsylvania the ability to access services at the earliest and most crucial time in their child's development. Additionally, Pennsylvania Act 212 (1990) was enacted into law to create greater opportunities "for the development of infants, toddlers and eligible young children who are handicapped in order to minimize their potential for developmental delay."

CURRENT PRACTICES AND INCONSISTENT USE OF ELIGIBILITY CRITERION ACROSS COUNTIES

In Pennsylvania, each county's early intervention advisor/administrator is responsible for interpreting the early intervention regulations to determine the process and parameters regarding testing, evaluation, and service delivery in their county. This leads to widespread confusion and inconsistency across counties – in process, eligibility, and equitable delivery of services.

Over time, counties have imposed restrictions on the use of the pathways to service, creating a hierarchy of the eligibility criteria. As such, some counties have minimized and/or eliminated the use of one or more eligibility pathways. This is inconsistent with the current state code (Title 55, Chapter 4226), and is in direct opposition to the spirit and intention of Act 212, which was to increase access opportunities for children and families. The practices adopted by individual counties to discourage use of or eliminate any of these eligibility criteria during the evaluation process limits access to crucial services for vulnerable and at-risk children.

In 2023, RCPA and EIPA conducted a joint survey of early intervention provider agencies to collect data regarding process and eligibility across the commonwealth. The survey revealed marked differences in process and adherence across regions to the standards outlined in Title 55.

- Nearly all counties in Pennsylvania have eliminated the use of 25% delay as an eligibility determinant.
- The use of Informed Clinical Opinion (ICO) is highly scrutinized by many county administrators.
 While now reinstated in most counties (after a period of elimination and/or mass disuse),
 evaluators report that they must take extra measures, investing additional time, to avoid punitive measures for using ICO.
- Some providers/stakeholders report inability to use ICO effectively due to the composition and training of Assessment Teams.
 - In many cases, there is one single clinician or provider conducting the eligibility assessment.
 - In the case where this provider is a generalist (DV, SI), this provider may lack the skills to fully assess specific areas of concern (such as motor or feeding).
 - In the case where the provider has specialized expertise in one domain, they may also lack the sensitivity necessary to determine eligibility in another area (like cognition or social development).
- Use of diagnosis as an eligibility mechanism is problematic in that its use is inconsistent. No consistent, standardized process exists across the commonwealth to determine if a diagnosis is not in accordance with the criteria established in Act 212.
 - While OCDEL states that an official diagnosis list does not exist, some counties have created unofficial lists. These lists differ by county.

- o Origin and maintenance of such a list is unclear.
- County entities and/or El Advisors are the arbitrators of the acceptability or deniability of diagnoses ("the list"). The process and criteria used for diagnosis exclusion is not transparent.
- o The qualifications of those making the determinations is unclear.

For example, Torticollis is a commonly treated diagnosis in early intervention. In the 2023 RCPA/EIPA survey, 25 respondents reported excluded diagnoses in their county and 100% of those respondents identified Torticollis as an excluded diagnosis. The importance of treating Torticollis within the first 3 months of diagnosis is clearly established (see references in cited paper) with negative developmental consequences evident for children whose treatment is delayed. Long-term deficits and compounding complications are preventable with early identification and treatment. In some counties, Torticollis is an excluded diagnosis. This limits access to crucial services by eliminating a mechanism for eligibility, and puts greater pressure on evaluators to find another route for eligibility. Inconsistent and inappropriate exclusions cause delays in necessary care.

PROBLEMS WITH CURRENT TESTING INSTRUMENTS AND PROCEDURES

One established eligibility mechanism for EI Services is testing values/scores. In Pennsylvania, the standardized assessments considered acceptable for use are extremely limited. In most counties, only one or two assessments are allowable (DAYC-2, BDI-3) and considered best practice to determine eligibility.

The assessments deemed acceptable by most PA counties are not well suited for a home-based or early learning environment, and are therefore unable for use as intended. Standardized administration, as designed by the developers, is not consistently possible; they are not normed and benchmarked for use in the manner in which they are delivered. For families where English is not the preferred language, the validity of such assessments is questionable. Furthermore, assessments conducted virtually lack the ability to standardize the environment, which further limits the validity of the assessment.

In the absence of a gold standard assessment for use in the early intervention setting, it is imperative that evaluators be permitted to select the tool that best measures the child and family's concerns and to use those scores for eligibility. Limiting the tools allowed for use in evaluations may further restrict eligibility of a child in need of services as the approved tools may not be designed to capture and reflect the deficits present.

SUBDOMAINS AND USE OF INFORMED CLINICAL OPINION

Pennsylvania's Early Intervention Program utilizes five areas/domains of development in addition to hearing and vision assessments for eligibility determination. These domains lack sensitivity and limit eligibility for children with more subtle presentations.

Under the umbrella of the five developmental domains, children may show a discrepancy between different subsets of these domains. (i.e., a child with weak gross motor skills, but strong fine motor skills or a child with weak expressive language skills, but strong receptive skills). A child may present with a valid specific concern in one subdomain of development, but a strength in the other subdomain. The aggregate scores skew the average test domain score and make the child ineligible for services. This is problematic, as discrepant subdomain scores can be indicative of underlying concerns that should be addressed.

As subdomain scores cannot be used for eligibility, some children who would benefit from early intervention services are not identified. Delayed intervention exacerbates underlying concerns and unnecessarily broadens the developmental gap. When a discrepancy in subdomain scores occurs, it is imperative that assessment teams be both allowed and encouraged to use other qualifying pathways (such as ICO) to ensure access to services for these children.

TRACKING

Developmental tracking for children who do not qualify for services is not a consistent practice. This results in children at risk for developmental delays of being overlooked. It places the responsibility on the family to re-engage with the early intervention system if concerns persist.

RECOMMENDATIONS FOR IMPROVEMENT

- 1. OCDEL should conduct a thorough needs assessment regarding current eligibility trends including input from a broad group of content experts.
- 2. OCDEL should then determine a transparent, comprehensive process, which includes credentialed developmental experts, prior to exclusion of any diagnosis to determine eligibility. This process and its findings should be regularly reviewed and updated as appropriate.
- 3. Mandate reinstatement of the use of all four pathways to eligibility. Disseminate a policy statement outlining acceptable use of all pathways; collect data on frequency of use of each pathway.
- 4. Eliminate consequences for use of ICO and/or 25% delay to determine El eligibility; provide education/counsel to counties that are out of compliance.
- 5. Ensure all EI assessment teams have a minimum of two qualified developmental evaluators who actively participate in assessment, eligibility determination, and plan (ER and IFSP) creation. A multi-disciplinary assessment team ensures more accurate assessment and greater collaboration across disciplines. This allows for more effective and sound decision making regarding eligibility and planning.
- 6. Disseminate guidance to allow assessment teams to select the standardized test administered and use supplemental testing tools based upon referral information, the child/family concerns, and testing environment.
- 7. Allow for subdomain scores to direct the use of informed clinical opinion. Educate evaluation teams on use of discrepancy analysis.
- 8. Expand the formal tracking process for children at risk who are deemed ineligible.

CONCLUDING REMARKS

Pennsylvania is among the nation's leaders in early intervention access. Our regulatory code and state legislation is clear with broad eligibility criteria to protect and provide access to services for children and families in Pennsylvania with developmental delays or disabilities. However, inconsistent execution and poor adherence to our code denies services to children who need them. We can ensure that all children who need early intervention services be found eligible by consistent adherence to the clearly established eligibility criteria.

EIPA paper PA Act 212