

Don't Be Too Late: Time of the Essence for Children with Developmental Delays

By Elizabeth Pagel-Hogan

Approximately 27% of children in Allegheny County under the age of 5 with a developmental delay may go undiagnosed. Missing this diagnosis means families face increased struggles when teaching skills to children and establishing routines and patterns. Eventually, the children may face major difficulties when they begin formal schooling in kindergarten or first grade.

The Early Learning Institute (TELI), in Pittsburgh, PA serves over 1200 children annually and offers unique resources for parents and children, birth to age 5, facing developmental delays. Pediatricians play a crucial role in helping parents access the support offered by TELI.

"Early diagnosis means better results for children," says Kara Rutowski, Executive Director of TELI for the past three years. "Our goal is to prepare a child for success in school. Over 70% of the children we serve enter kindergarten with minimal support, like speech therapy, which is significantly better than state benchmarks of 23-28%. We want them to function at the level of their typically developing peers."

Early diagnosis is essential to helping parents identify and understand the unique nature of their child's developmental delay. From birth to age 5, it is significantly easier to help children master simple techniques and modifications that are key to entering school with minimal or no support. Many children who receive early intervention operate on the same level as their normally developing peers.

Developmental delays can have a serious impact on school readiness. The Center for Disease Control (CDC) estimates that 17% of U.S. children have a developmental or behavioral disability, including autism, intellectual disabilities, and/or Attention-Deficit/Hyperactivity Disorder (AD/HD). Current research estimates that less than 50% of the delays are identified before starting school, and this failure to catch the issue means significant delays are already in place and opportunities for early intervention have been missed.

Being a parent is hard but being a parent when your child has extra-special needs can be especially daunting. Pediatricians can play an important role in helping parents determine if their child is going through an appropriate developmental phase or if they are struggling to meet the next milestone.

Rutowski describes TELI's services as part of the toolbox that pediatricians can use to support parents and serve the children.

"Doctors are inundated with information," argues Rutowski. "If we're doing our job well and the pediatrician is pulling out the tool of early intervention from TELI, that leaves the pediatrician free to address medical issues and streamlines their work. Diagnosing and treating an earache is simple. When the problem is behavioral or cognitive, the decision tree and resources aren't as clear."

"Pediatricians can really help parents learn what behavior is normal and what isn't but they often have to maintain a delicate balance with parents, especially new parents," Rutowski explains. "Pediatricians don't want to dismiss parental concerns but they also don't want to cause parents panic. Some parents are resistant to further evaluation or assessment."

"TELI is a great option," reports Debbie Uram, Director, Early Intervention Services, with over 35 years experience in early intervention services. "Parents do not have to commit to a full assessment. They can bounce ideas off the specialists at TELI about their child's development and therapists are able to advise parents if their child needs a full assessment and provide the appropriate referral information."

Parents often call TELI out of the blue to ask questions. Even grandparents visiting a nearby veteran's service office have dropped in to ask about appropriate developmental stages. To meet this need, TELI is preparing to introduce a portal that parents can use to submit questions to therapists via the TELI website (www.telipa.org).

"It will function like a web triage for question and answers," says Rutowski. "We're evolving, using current technology and trying to reach parents where they are. As a non-profit we're also trying to be cost-effective."

Parents who feel their child may have a developmental delay can call TELI at 412.922.8322 or their pediatrician for advice. TELI therapists can provide some basic information and if the therapist feels the child would benefit from an assessment, the family would be encouraged to call the Alliance for Infants and Toddlers (412.885.6000), the service coordination agency. A service coordinator will listen to the parent's concerns and set up an evaluation with the appropriate therapists in the child's home. If the child is eligible, parents can choose to receive their therapies from TELI and specific goals will be addressed to meet the child's and families' needs.

"Let's say your child doesn't speak very well," Uram describes. "A pediatrician, neighbor or other parent who has used TELI's service might encourage the parent to call might encourage a parent to call us directly and we can talk about their speech concerns. At this point, parents are gathering information to help them decide how they would like to proceed. They do not have to commit to an evaluation; rather, we will provide them with the facts and encourage them to pursue an independent assessment through Early Intervention if our professional staff feel that it is war-

ranted. In many instances, we can alleviate their fears by telling them that a specific speech concern is developmentally appropriate at that time."



TELI physical therapist Kay Donovan works on movement with a child

There is no cost to parents for the assessment or for any of the therapy provided by TELI and all therapy is provided in the child's home environment or in a community setting.

"Nobody knows the child better than the parent," Uram said. "We like working in the homes because you are partnering with the family to help the child in their most comfortable environment. All activities are play-based and developmentally appropriate. They are also routines-based. So if a parent is having trouble at bath time, the occupational therapist schedules an appointment at bath time. Therapy helps the overall family environment and reduces stress levels."

For more information, visit www.telipa.org.



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