

Early Childhood Behaviors

As expected, major developmental milestones were delayed because Laura was significantly premature. She started walking at 18 months. She started talking relatively late.

She was still using very few words by the time she was three. Frequent tantrums started around that time. She would stand in one place and spin around and around, never falling.

She practiced repetitive play, building single block towers, but no other structures. She spun the wheels on toys, over and over again. She rarely made eye contact.

Laura became fixated on a certain favorite dress, screaming for it when she had to wear other clothes. She was obsessed with wearing white socks and black Mary Jane shoes, which had to be removed after she fell asleep.

Fingernails and toenails had to be trimmed with nail scissors while Laura was sleeping, sometimes only a few nails a day. This was the only way to get the job done without struggles and screaming. All of this was because she had sensory perception issues that I knew nothing about.

Hair was kept short because she couldn't tolerate even the wide-tooth comb we used for more than a few seconds at a time. Brushing her teeth was a tremendous struggle. Toilet training was a distant dream.

Diagnosis Was a Lengthy Process

Laura's pediatrician referred her for evaluation by a speech pathologist when she was almost three. She was diagnosed with a severe receptive and expressive language disorder. Laura's behaviors continued to increase in severity.

She was referred to a major university medical center to be evaluated by their developmental pediatric team. It took months to get in for the evaluation. This is still a common occurrence.

I had hoped to get Laura involved in school programming that year, but the diagnosis of severe receptive and expressive language disorder with autistic-like behaviors was delivered at age three-and-a-half, in April. It took a few weeks to get a meeting with the school to set up an Individualized Education Program (IEP) for Laura.

I met with the IEP team at the beginning of May. School broke for the summer a few weeks later. We were able to get a one hour visit from a special education teacher each week through that summer until school started in the fall.

Need for Additional Assessment and Diagnosis

Laura's diagnosis provided the basis for getting her into a special education developmental preschool with services to address her autism. Laura attended this preschool for two years before moving on to kindergarten. She was supported by special education teachers, a speech and language therapist, an occupational therapist, an autism specialist, and paraprofessionals.

Laura interacted with other students with disabilities and with typical peers included in the classroom. This was a great learning experience and prepared her to go on to kindergarten.

Just before the school year ended, a sympathetic preschool teacher pulled me aside to tell me that Laura should have another evaluation to "get the (autism) label" or she would lose some of her services after kindergarten ended. This was never mentioned in any of our formal meetings.

Delays in Getting a Diagnosis and Impact

Getting an accurate diagnosis is an important step toward securing the supports that children with ASD need to have to ensure more successful life outcomes. The backlog of patients waiting for evaluations continues across the United States. Parents have come to refer to the period that follows the recognition that your child needs an evaluation to actually getting the evaluation as the diagnostic odyssey.

Part of the reason for this delay is the lack of qualified providers. The evaluations are also lengthy, costly, and involve a team of professionals. Another barrier to evaluation is the discomfort that primary care physicians have about diagnosing autism in their patients.

Anything that slows down a referral to specialists further delays the process of obtaining a developmental evaluation and diagnosis. All of these roadblocks are a serious disservice to a child who needs the earliest possible intervention to achieve a more favorable life outcome.

The Child Find Mandate and the Individuals with Disabilities Education Act

In 2004, the Individuals with Disabilities Education Act (IDEA) was amended to require that school systems participate in the Child Find mandate. Parents and school systems are responsible to identify children who may have learning disabilities.

All children with disabilities, from birth to age 21, are covered. This includes infants, toddlers, children who are homeschooled, children in private schools, migrant children, homeless children, highly mobile children, and children who are wards of the state.

This mandate applies to all children, even if they are receiving passing grades and advancing from grade to grade. It does not require that children be labeled or classified by their disability to receive an evaluation.

The purpose of this mandate is to encourage states to provide early intervention services for infants and toddlers. States are required to provide special education services to children with disabilities by age three (Wrightslaw, 2018).

First Screenings for Autism Still Occur Relatively Late

Despite the availability of early autism screening tools that can help us to identify a child with autism as young as 18 months old, the average age at diagnosis of ASD in the United States remains at age three-and-a-half to age five (Gordon, Foster & Peacock, 2016). The CDC states that less than half of the children they have identified on the autism spectrum received their diagnosis by age 4.

Although 85 percent of children diagnosed with autism had developmental concerns noted in their medical records by age three, only 42 percent received their diagnosis by that time. This time lag may delay children with autism from getting the services they need. It is critical to each child's future that they are identified and then connected with early intervention services (CDC, 2018).

Free Resources to Monitor Childhood Development

Free resources are available from the CDC's *Learn the Signs, Act Early* program. This program provides resources to monitor childhood development. These resources are available in both English and Spanish. They provide research-based developmental milestone checklists for children, starting at two months old.

CDC's Milestone Tracker App, available for Apple and Android, is a convenient way to track a child's development and share the data with the child's healthcare provider. More information on this program and the app are found at www.cdc.gov/ActEarly.

Tracking data closely, either on this app or by keeping good written records, is critical to providing accurate data to the child's healthcare providers. This should help shorten the path from concerns to diagnosis.

Early Intervention Services Make a World of Difference

Laura's diagnosis, and the services that she has received because of it, have made an incredible difference in her life. Although she continues to struggle with social interactions and communication issues, she is independent in most areas of her life. Since we are able to detect autism earlier today than when Laura was a child, we should be able to help even more children with autism to have the best possible life outcomes.

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