

California Leadership Education In Neurodevelopmental and Related Disabilities

Authors: Armida Ochoa (Family Support), Abigail Ristow (SLP), Adriana Aguilar (Family Support), Karen Camero (Pediatrics), Julia Haruno (Pediatrics), Sonia Packer (Public Health)



Increasing Access to Autism Spectrum Evaluations through the Regional Center

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Introduction:

This policy aims to change the Regional Centers' age requirement for evaluation of autism spectrum disorders (ASD), from 32 months to 24 months. The ultimate goal is for children to receive the diagnosis of ASD in a timely manner, in order to access appropriate services.

Background:

In 2020, the CDC reported that approximately 1 in 54 children in the U.S. is diagnosed with an autism spectrum disorder (ASD), according to 2016 data. The impairments from ASD not only affect the diagnosed individual but also their caregivers, family, teachers, and community. According to Autismspeaks.org, autism costs on average an estimated \$60,000 a year through childhood, with the bulk of the costs in special services and lost wages related to increased demands on one or both parents. Costs increase with the occurrence of intellectual disability. Emerging evidence suggests that autism spectrum disorder can be diagnosed as early as 18 months with very reliable results at 24 months. Furthermore, research shows that early intensive behavioral intervention positively affects ASD core deficits. However, currently many regional centers will not evaluate children under 32 months of age and private ASD evaluations can be very expensive and/or they have extremely long waitlists. The confirmed diagnosis of autism is required to access specialty services, which vary widely on the basis of socioeconomic status, race, and ethnicity. As a result, children miss out on the earlier diagnosis and timely intervention for necessary treatment. Barriers to diagnostic services have the potential not only to affect a child's long-term development but also to increase existing disparities in autism care.

Policy Recommendation:

We propose a policy change requiring all Regional Centers to initiate ASD evaluations at age 24 months to improve early diagnosis, intervention, and long-term outcomes. This policy change would focus on increasing access to ASD evaluations for children ages 24 months to 31 months. This population is currently underserved and experiencing delays in diagnosis and services due to existing policy that Regional Center ASD evaluations are conducted only after the child is 32 months or older. A legislative change is necessary to require Regional Centers to provide access to these crucial services with a timeline that matches current evidence, ASD evaluations are reliable and accurate as early as 18-24 months of age. Possible costs related to this proposal include hiring additional qualified staff (e.g., psychologists, speech language pathologists, developmental pediatricians) to complete these evaluations. The cost of not pursuing a change in this policy is reflected in lower performance outcomes later in life, as data shows that the cost of caring for Americans with autism reached \$268 billion in 2015 and is estimated to rise to \$461 billion by 2025, in the absence of more-effective interventions and support across the life span.

The California Lanterman Developmental Disabilities Services Act, outlines the rights to services and support for individuals with developmental disabilities age 3 years and older, including those with ASD, and provides support to families. This proposed policy change would support increasing access to earlier intervention, improve outcomes in academic and social participation, and theoretically decrease the burden of the Lanterman Act to provide additional services for these families based on severity of need.

Children ages 0-3 years with ASD may qualify for Regional Center early intervention services through IDEA part C. These services primarily focus on speech and language, gross or fine motor delays. However, children with ASD, require additional behavioral and social/communication interventions (ie. applied behavioral analysis therapy or floor time). These behavioral services are not implemented through the Regional Center until a diagnosis of ASD is made. However, many Regional Centers do not provide ASD evaluations and diagnoses until age 32 months. Thus, there is a delay in implementing appropriate behavioral and social/communication interventions for children with ASD. If the diagnosis of ASD is made through an outside provider, behavioral interventions can be implemented and covered by the insurance, earlier than the 32 month milestone which creates disparities in developmental outcomes in the short and long term.

Summary of proposed policy changes:

- Advocate for earlier formal autism evaluations and diagnoses through RC.
- Expansion of social/communication and behavioral therapies (ie. ABA therapy, floor time) for children with ASD less than 3 years of age.
- Equity in the referral, evaluation and service process regardless of insurance status.

- Ensure methods to facilitate referral and communication process with RC (parent navigator, case manager, family support team).
- Advocate for creation of community and integration programs (through schools/daycares) to reinforce social, communication, behavioral and adaptive skills in patients diagnosed with ASD.
- Improve the transition process for children after the age of 3. Some clients will require continued services through RC while others may need support while they transition to the school district.

Evaluation of policy change:

- Evaluate the age of referral to Regional Center from primary doctors.
- Evaluate the number of children being assessed for ASD by the Regional Center before the age of three.**
- Compare the mean age of autism diagnosis before and after the policy change.
- Perform periodic Regional Center audits to ensure referrals and evaluations are being done in a timely manner.
- Monitor time lapsed from diagnosis of autism to initiation of services.
- Monitor child development at each well child check, to evaluate improvement after initiation of services.

References:

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