

# PROMISING PRACTICES IN HOME AND COMMUNITY-BASED SERVICES

## California – Single Process for Diagnosis and Service Delivery

### Issue: Early Diagnosis of Autism Spectrum Disorders

#### Summary

Two multi-county regions in California established one-stop clinics to diagnose autism spectrum disorders (ASD) and coordinate service planning across the education and developmental disabilities systems. Both regions also established ongoing collaborative teams to coordinate supports and improve the local service system for children with ASD. An evaluation reported a four-month reduction in the average age of ASD diagnosis.

#### Introduction

The number of children diagnosed with autism spectrum disorders (ASD) has increased dramatically in recent decades. A study from the Centers for Disease Control estimates that one of every 150 children has an ASD<sup>1</sup>. According to the National Research Council, research has suggested that intensive interventions can improve functioning for many children with ASD<sup>2</sup>. An early diagnosis is critical to start services as quickly as possible.

**Early diagnosis is critical to start services quickly.**

Diagnosis and treatment may be delayed, however, for several reasons. Clinicians often have different understandings of autism spectrum disorders. In addition, coordinating treatment can be difficult for people who need public funding for these frequently expensive treatment models. Both the education and developmental disabilities systems serve children with ASD. These systems may be fragmented, however, with their own processes and standards for diagnosing and serving children with ASD.

In two regions in California, the developmental disability services system, education agencies,

and families worked together to streamline diagnosis and treatment. Each region established one-stop clinics to perform comprehensive diagnostic evaluations and coordinate services from the appropriate system.

#### Background

Local education agencies (LEAs) are responsible for providing special education and related services to eligible children as mandated by the Individuals with Disabilities Education Improvement Act of 2004. School systems must work with parents to develop an Individualized Education Program that specifies planned educational services for each child. For children with ASD, the education services may include one of the intensive intervention methods aimed at young children with ASD.

In California, the developmental disability services system is responsible for providing services a child needs beyond the LEAs' services. These supports are administered by 21 non-profit "Regional Centers." Families must use their own funds, private insurance, the education system, or other resources before Regional Centers pay for services.

For children with ASD under age 3, the centers provide early intervention services according to an Individual Family Service Plan, also mandated by IDEA 2004. Early intervention can include a variety of therapies and supports, including behavioral interventions for children with ASD.

<sup>1</sup> Centers for Disease Control *Prevalence of the Autism Spectrum Disorders (ASDs) in Multiple Areas of the United States, 2000 and 2002* Released in 2007. Autism spectrum disorders include autism and similar pervasive developmental disabilities such as Asperger's syndrome.

<sup>2</sup> National Research Council *Educating Children with Autism* 2001

For school-age children, youth, and adults, the Regional Centers help maximize independence. Services can include respite and family training regarding intervention strategies. State law created an entitlement for people with the specific diagnosis of Autistic Disorder (a.k.a. autism), but not for other autism spectrum disorders. These supports are funded by state general revenue and a Medicaid home and community-based services waiver for individuals with developmental disabilities.

### Intervention

Two Regional Centers and their LEAs established joint one-stop clinics where children receive comprehensive diagnostic evaluations and service planning. Valley Mountain Regional Center is located in a mostly rural, six-county area that includes Stockton and Modesto. North Bay Regional Center serves Napa, Solano, and Sonoma Counties. Each region has established two clinics.

Children are usually referred to the one-stop clinics through families, pediatricians, or day care because they have speech delay. Early intervention specialists screen children for autistic behaviors and if appropriate, children are referred to the diagnostic clinics for a comprehensive evaluation. All clinics have a multi-disciplinary team including psychiatrists, psychologists, speech therapists, and behavior specialists.

The clinics have staff from Regional Centers and the school system working together to assess children and provide information about services. The clinics follow a best practices guide that California's Department of Developmental Services developed for diagnosing ASD. Parents can obtain diagnoses from other clinicians, but the one-stop clinic will conduct its own evaluation unless the clinician follows the best practices guidelines.

The regions use different funding sources. In North Bay, the school districts pay for assessments on a fee-for-service basis. Valley Mountain Regional Center uses state general revenue funds to support its clinics.

Both regions also established ongoing collaborative teams to continue working on autism issues. These groups are comprised of the Regional Center, schools, parents, and providers. These teams develop treatment guidelines; conduct training sessions for parents and professionals regarding ASD; and evaluate the process to ensure people have appropriate access to services after diagnosis.

### Implementation

In both areas, the development of one-stop autism clinics started with a partnership between the Regional Center director and a few local special education administrators. Both systems noticed a high number of children with ASD and inconsistencies in diagnosis and services, and were eager to standardize and improve diagnosis and service delivery. In each region, the Regional Center director invited all the local special education administrators, parents, case managers, and autism experts to attend a kickoff meeting to solicit ideas for improvement.

**Both clinics were developed within larger efforts to improve supports for children with ASD.**

Both regions trained local professionals using the Learning Collaborative model for process improvement. Autism experts worked in partnership with educators, Regional Center staff, and parents to develop the content and format of the training sessions. The collaborative process included discussions of how to improve the day-to-day process for serving children with ASD, as well as learning the state of the art for ASD diagnosis.

Agencies in Valley Mountain started collaboration in 1994, using state funds from the Regional Center budget to support the planning. After several meetings, they decided to establish a one-stop autism clinic to provide a diagnosis at the earliest possible age. They also established an interagency autism team to provide a formal structure for ongoing collaboration.

North Bay started more recently, in 2002, with a state-funded grant from California's Department of Developmental Services to implement the best practices guide for ASD diagnosis. The grant was part of the state's ASD Learning Collaborative initiative, which awarded grants for

**Clinics follow a best practices guide for diagnosing ASD.**

Regional Centers to use the Learning Collaborative model and best practices guide to improve diagnosis and evaluation of children with ASD. As part of the state's initiative, Valley Mountain assisted North Bay in developing its collaborative process.

To raise awareness about the clinics, both regions reached out to schools, parent organizations, service providers, clinics, and health insurance companies. An important outreach technique for the North Bay Regional Center was a 5x8 card with a brief autism screening instrument and the clinic's contact information. The card informed people about early warning signs of ASD, as well as who to contact for assistance.

**Discussion Questions:**

- 1. How can the benefits of the joint clinics be applied to rural and frontier areas where a specialized clinic would not be viable?**
- 2. How can states apply this concept to improve early diagnosis of ASD?**

**Impact**

Both the Regional Centers and LEAs report greater consistency in diagnosis and treatment strategies. For North Bay Regional Center, an evaluation reported a statistically significant reduction in the age children were diagnosed with an ASD: from 38 months to 34 months.

**Contact Information**

For more information about the joint autism clinics, contact Tara Sisemore-Hester, Valley Mountain Regional Center, at (209) 955-3262 or [TSisemore@vmrc.net](mailto:TSisemore@vmrc.net), and Dr. Patrick Maher, North Bay Regional Center, at (707) 256-1111 or [patrickm@nbrc.net](mailto:patrickm@nbrc.net). California's best practice guidelines for diagnosing ASD are available at <http://www.dds.ca.gov/Autism>.

One of a series of reports by Thomson Healthcare for the U.S. Centers for Medicare & Medicaid Services (CMS) highlighting promising practices in home and community-based services. The entire series is available online at CMS' web site, <http://www.cms.gov>. This report is intended to share information about different approaches to offering home and community-based services. This report is not an endorsement of any practice.