

California ASD Collaborative

Collaborative on Improving Services for Children and Adolescents Suspected of Having Autistic Spectrum Disorders (ASD)

Collaborative Charter

The Challenge

Throughout California there is an immediate need for improved and consistent approaches to the screening, diagnosis and assessment of children and adolescents suspected of having autistic spectrum disorders (ASD). Since 1995, the California Department of Developmental Services (DDS) has documented a steady increase in the number of individuals diagnosed with ASD. Although autism has been recognized for more than fifty years, the recent increase in the number of children diagnosed with this condition has escalated concern among parents and professionals. Responding to a 1999 report from DDS documenting the increase in number of children diagnosed with this disorder and to concerns of parents and the professional community, the Legislature passed Assembly Bill 430, acknowledging the need for consistency and accuracy in the diagnosis of ASD.

As a result, a statewide effort has begun to improve screening, diagnosis and assessment of persons with autistic spectrum disorders. The effort is lead by DDS, regional centers, interested clinicians and educators, and parents of children with ASD. The statewide initiative focuses on collaboration with interested persons and organizations—working together to 1) change clinical and organizational practices and 2) share information about what works best, lessons learned and the pitfalls to avoid. This collaboration recognizes that although many of the essential elements of good services for persons with ASD are known, there is a gap between what is known and the services that are provided. As a result, service delivery often lacks coordination, timeliness and comprehensiveness, which often leaves families feeling frustrated and challenged in meeting the day-to-day needs of their child or adolescent.

There are several tools and resources that have been developed in support of this collaboration. DDS has recently supported and the Association of Regional Center Agencies (ARCA) has endorsed the development of *Autistic Spectrum Disorders: Best Practice Guidelines for Screening, Diagnosis and Assessment (Guidelines)*. The *Guidelines* is the product of nearly a year's work by experts in the field. It provides recommendations, guidance and information about current "best practice" in the field. Additionally, it provides a framework for the development and broad implementation of educational and

training programs designed to reach professionals who in their day-to-day practice may encounter individuals suspected of having an ASD. The *Guidelines* is not intended as policy or regulation, but as a tool designed to help health care providers, diagnostic teams, educators and families make informed decisions regarding ASD. A publication that summarizes the *Guidelines* has also been developed. The *Quick Reference Guide for Autistic Spectrum Disorders: Best Practice Guidelines for Screening, Diagnosis and Assessment* facilitates use of the more comprehensive *Guidelines*.

The collaborative is targeted at all interested persons who provide services for persons suspected of having an ASD—primary care providers, schools, mental health providers, academic medical centers and others that partner with regional centers to provide services for persons with this disorder. These interested persons and organizations come together into “learning teams” coordinated by regional centers throughout California. Each team commits to working to meet the strategic goals and objectives of the collaborative, and to measure and report data that indicate whether or not the goals are being met. The California ASD Collaborative has set an ambitious strategic goal: to improve the screening, diagnosis and assessment of all persons suspected of having an ASD.

Ten core concepts guide the work of the collaborative. These include: *DSM-IV* is used for diagnostic classification; early identification leads to higher quality of life; informed clinical judgment enhances diagnostic accuracy; ASD represents different challenges throughout the life span; confidentiality is balanced with informed exchange; interagency collaboration and problem solving should be promoted at every opportunity; an interdisciplinary process yields a comprehensive profile; evaluations are family-centered and culturally sensitive; timely referral and service coordination improve outcomes; best practices involve constant review and training.

Collaborative Mission

Regional center “learning teams” work together to implement selected best practice recommendations from the *Guidelines*. Teams address issues related to 1) diagnostic evaluation, 2) assessment for intervention planning, and 3) formulation, presentation and documentation of findings. The teams collect and report data on the outcomes of their work using uniform measures developed by the collaborative staff and faculty. Each learning team also has the opportunity to select additional content for improvement based on an assessment of their current clinical and organizational practices.

The development of the teams will occur in stages. In Spring 2003, North Bay Regional Center and its partner organizations volunteered to serve as a prototype for the statewide collaborative effort. Based on the lessons learned from improvements implemented by this team over a six month time period, five additional teams will be added to the statewide collaborative in the Fall 2003. Another five teams will be added to the statewide collaborative in the Spring 2004. Criteria will be developed to assist in the selection of teams to be added to the collaborative. Executive leadership and the capacity to implement data collection and organization change will be some of the criteria for selection.

Led by expert faculty, the teams will learn about “best practice” content from the *Guidelines* and, based upon their team deliberations, organizational changes will be implemented to achieve the desired outcomes. Collaborative links will be established between the faculty and the participating teams.

The long-term goal of the collaborative is to maximize the quality of services for persons suspected of having an ASD. The collaborative seeks a transformation in the nature and experience of services for this disorder. This includes identification of the disorder and referral for developmentally appropriate treatment at an earlier age. It includes health care providers who listen carefully to the concerns of parents about their child’s development. It includes involvement of primary care providers (PCP) in the treatment of persons they refer for diagnosis and intervention. Finally, it includes clinicians with confidence in their ability to provide needed services or make appropriate referrals. This will be achieved by implementing a system-wide model of service delivery that focuses on assuring the implementation of evidence-based clinical knowledge and strong support for families.

Collaborative Goals

Learning teams will collect data to document improvements in the following areas:

Diagnostic Evaluation

- 1) The diagnostic evaluation process includes the six components specified in the *Guidelines*.
- 2) Primary care providers participate during the diagnostic evaluation process.

Assessment for Intervention Planning

- 3) The assessment for intervention planning employs an interdisciplinary team approach.
- 4) The assessment for intervention planning uses information gathered from multiple settings.

Formulation, Presentation, and Documentation

- 5) The final report includes the eight components specified in the *Guidelines*.

Family-centered Care

- 6) Parents and caregivers feel satisfied about services.