

## **Screening and Diagnosis Subcommittee Report**

DRAFT VERSION 3 – May 7, 2008

### **I. SCREENING AND DIAGNOSIS FINDINGS**

1. Public awareness of individuals living with autism spectrum disorders (ASD) in Nevada and nationwide has increased markedly in the new millennium because of increased media and internet coverage. Greater awareness of autism has not necessarily increased understanding of the disorder or knowledge of the available services. Many families remain misinformed, confused and frustrated in their efforts to obtain a diagnosis for their child or to access appropriate autism services supports.
2. Public service providers include Nevada Early Intervention Services, the 17 independent school districts, Regional Centers and to a lesser extent the Department of Training and Rehabilitation. These public service agencies have different eligibility criteria and levels of professional expertise in providing the specialized services needed to build functional skills or to address the core features of autism. Families may be receiving services from more than one public service provider simultaneously. Services across service agencies are poorly coordinated if at all. Many families also seek services from private rehabilitation agencies employing licensed speech-language pathologists, occupational or physical therapists; however the number, duration or frequency of those private services are typically limited by health insurance practices. Some families may be able to pay for services through Medicaid, but those services must meet *medical necessity* criteria.
3. The number of children identified with ASD in Nevada is only 50% of the expected number (IDEA, 2003) based on national prevalence rates of 1 in 150 (CDC, 2007).

4. The Individuals with Disabilities Education Act (IDEA) and the Nevada Administrative Code (NAC 388.430) allows children under age six to be made eligible for early intervention and early childhood special education services under a generic category of Developmental Delay (DD). While this is allowed by IDEA and NAC, it is not required and children with ASD may be made eligible under the ASD category. In Nevada many toddlers and pre-school children with ASD are receiving services under the DD category thereby concealing the actual numbers of children with autism spectrum disorders. Despite public agency assurances that individualized service plans are based on need and not eligibility category, parents frequently complain that children with specific ASD eligibility do not receive the specialized and intensive treatment services need by this population.
5. National data on early identification indicates that most parents become concerned about their child's development between 15 and 18 months of age but may have difficulty getting their concerns taken seriously or acted upon. This often results in significant delays between the time parents raise the concern and the eventual diagnosis. Many parents report delays of two to three years, or longer. Results of a survey conducted by the Nevada Autism Summit in 2006 indicated that many Nevada parents share in that unfortunate experience.
6. Nevada does not have a uniform system for identifying children who may be at risk of developmental delays and/or ASD. Lack of developmental surveillance and screening is a critical barrier to early identification of ASD.

7. There is a significant lack of data on Nevada autism prevalence and service utilization on which to base changes in policy, formation of new services, and estimate resource capacity and needs across the state.
8. Pediatricians are encouraged by the American Academy of Pediatrics (AAP) to conduct developmental surveillance during well-child visits and developmental screening and autism-specific screening on a periodic schedule (using standardized screening instruments rather than clinical judgment alone). Research on pediatrician practices, however, indicates that lack of time, lack of reimbursement and lack of use of standardized developmental screening tools are barriers to this practice (Sices, 2007).
9. According to the U.S. Department of Health and Human Services (2005) at least 60% of families in Nevada do not have a “Medical Home”. This means these children do not have a personal doctor or nurse nor do they receive care that is accessible, comprehensive, culturally sensitive and coordinated. Families may access intermittent medical services for their children through hospital emergency rooms, but no one is monitoring the health or development of these children over time.
10. Many communities across Nevada do not have access to professionals who are trained to assesses for treatment planning or TO diagnose ASD. According to the Nevada Administrative Code, an appropriate multidisciplinary team considering the eligibility and treatment plan for a child with ASD must consist of: a school psychologist; a speech-language pathologist; a teacher of special education; a person with a specialized knowledge of autism; the regular classroom teacher of the pupil, or, if none, a person qualified to teach the pupil; a parent of the pupil; one or more persons who have sufficient knowledge of the pupil to interpret information relating to the pupil’s social, emotional, developmental and familial condition (such persons may include an

administrator of the school, a nurse, a counselor, a school psychologist or any other certificated or licensed professional (NAC 388.387). Without the informed, written consent of the parent(s), the school district may not share information related to the eligibility or treatment plan of a child with autism with the child's primary care physician.

11. There is a lack of effective collaboration and coordination among agencies that provide ASD diagnostic and intervention services for individuals with ASD leading to confusion for families who are accessing services through multiple state or local agencies.
12. There are significant challenges in ensuring that minority children in Nevada have access to autism screening, diagnostic and treatment services. Children from culturally and linguistically diverse populations are not being identified with ASD and are not receiving treatment services. According to the University of Nevada Center for Health Statistics and Informatics (2008 draft report), only seven percent of children receiving ASD services in Nevada are members of culturally and linguistically diverse populations.
13. Access to services is negatively impacted by factors such as location (rural vs. urban), socio-economic status (parents who can pay for services out-of-pocket can access more services), educational level (parents who can access information via print or the internet are better informed about available services and supports).

**II. SCREENING AND DIAGNOSIS GOAL:** *Ensure that all children in Nevada, regardless of race or ethnicity, primary language, education or socio-economic status have access to autism screening, diagnostic and treatment services prior to age 3, and preferably before age 2 years.*

### **III. SCREENING RECOMMENDATIONS**

1. The Department of Health and Human Services will conduct an ongoing public awareness campaign to increase the awareness of the early signs of autism, and increase access to developmental and autism specific screening:
2. The Department of Health and Human Services will create web-based autism services linked to the Nevada State Health Division's website that features web-based learning opportunities, audio-visual and print resources and interactive discussion forums.
3. The Department of Health and Human Services will widely distribute fliers advertising the statewide toll-free number for the Nevada State Health Division's ***Autism Training and Technical Support Center*** where families can access free developmental screening for their child.
4. The Department of Health and Human Services will use public service announcements on radio and television to increase awareness of the early signs of autism and to link families to screening and diagnostic services.
5. The Department of Health and Human Services will develop a statewide Neurodevelopmental Disorders Registry. Designate autism spectrum disorders as a reportable condition in Nevada for the purpose of determining the incidence and prevalence of this condition in our state.
6. The Department of Health and Human Services will improve statewide professional capacity for early identification of ASDs via: Training workshops on the use of standardized developmental and autism-specific screening tools for early care and education providers who have ongoing contact with children (i.e., community childcare providers, early intervention and early childhood educators, Division of Child & Family Services staff, Welfare staff, and Early Head Start and Head Start teachers).

7. The University of Nevada System will embed best practice methods for early identification and referral into pre-service courses for related services in higher education (special education, general education, and ancillary services (e.g., speech-language pathology, psychology).
8. The Department of Health and Human Services will require that all health care providers (pediatricians, primary care physicians, emergency room physicians, Quick-Care staff, nurses, community health nurses, WIC staff) have access to training in the recognition of “red flags” associated with ASD, the administration of screening tools and utilization of appropriate referral sources. The goal of this recommendation is to lower the age at which children are identified with ASD and other developmental disorders in Nevada with an ultimate goal of identifying children between 18 and 24 months of age.
9. Per the American Academy of Pediatrics (2007) recommendations, the Nevada Health Division will ensure that all children are screened with a standardized developmental tool at specific intervals (i.e., at the 9-, 18-, and 24- or 30-month well child office visits) and an autism-specific screening tool at age 18 months and 24 months regardless of whether a concern has been raised or a risk has been identified.
10. The Nevada State Health Division will work with appropriate agencies to ensure that more children and youth in Nevada have a medical home where health care services are accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally-competent.

#### **IV. DIAGNOSIS & ELIGIBILITY RECOMMENDATIONS**

1. All professionals involved in diagnosing ASD should follow current best practice parameters for clinical diagnoses of ASD (See the American Academy of Neurology and

the American Academy of Pediatrics guidelines). The Nevada State Health Division will ensure that current information on ASD diagnostic best practices is disseminated to appropriate professionals on a periodic basis throughout the year.

2. Diagnostic evaluation and assessment should be conducted by a team of trained professionals experienced in diagnosing ASD and should include a physician and a licensed clinical or school psychologist, a licensed speech-language pathologist, and a licensed occupational or physical therapist. Diagnosis of autism is made by observation of a child over time across several meaningful settings and involving opportunities to interact with familiar and unfamiliar adults and children. A careful history of the child and family (i.e., birth, medical, developmental, social and family histories) should be recorded and considered in a differential diagnosis of autism.
3. Increase the capacity of trained professionals capable of diagnosing ASD through the following activities:
  - a. Create a *Center of Excellence in Autism* in Nevada which includes representation from the University of Nevada system, practicing physicians, consumers, school districts, and state agency personnel. The *Center* and the Nevada Health Division's *Office of Autism Training and Technical Assistance* will provide ongoing training and support to professionals working with children and families living with autism
  - b. The Nevada Health Division will develop and disseminate statewide standards for ASD screening, diagnosis, and referral and develop and disseminate a model plan of care to improve consistency of services for children with ASD across systems of care in Nevada.

- c. The Departments of Education and Health and Human Services will develop a *train-the-trainers* model in which teams of professionals selected from diverse Nevada communities in are trained in best practices for diagnosing ASD. These teams would then go back to their communities and provide ASD diagnostic services. These community diagnostic teams will have ongoing access to the Nevada Health Division's *Autism Training and Technical Support Center* and the proposed *Center of Excellence in Autism* in order to provide services the conform to best practices.
4. Nevada's independent school districts and Nevada Early Intervention Services will ensure that each child who meets the criteria for one of the several autism spectrum disorders will have *Autism Spectrum Disorder* recorded as his or her eligibility status. The generic *Developmental Delay* status will not be used for children meeting the criteria for ASD.
5. Nevada's independent school districts and Nevada Early Intervention Services will demonstrate that they have appropriately trained Multidisciplinary Teams (MDT) to provide competent evaluation and assessment of ASD and, with the family's informed consent, share the results of that testing with the child's primary care physician. The purpose of this recommendation is to provide information to primary care physicians to facilitate a medical diagnosis of autism for their patients, especially in rural Nevada communities where significant barriers exist related to distance from specialty medical services, social economic status, cultural and linguistic diversity and educational level of families. A medical diagnosis of ASD permits families to pursue other services. Early intervention programs and school districts will demonstrate that they have informed

families of the availability of those services and actively assist families in obtaining a medical diagnosis and referral to other public and nonpublic services.

6. The recommendations in this section require additional funding to support public awareness campaigns, improved screening and diagnosis of ASD using competently trained professionals, and improved access by families living with autism to the full range of available public and nonpublic services.