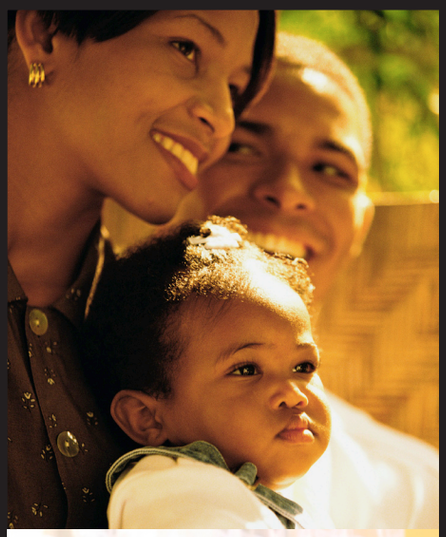

THE CALIFORNIA LEGISLATIVE
BLUE RIBBON COMMISSION
ON AUTISM REPORT

An Opportunity to Achieve Real Change for Californians with Autism Spectrum Disorders

SEPTEMBER 2007

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THE LEGISLATIVE OFFICE BUILDING
1020 N STREET, ROOM 359
SACRAMENTO, CALIFORNIA 95814
PHONE 916-319-3541 • FAX 916-319-3547
HTTP://SENWEB03.SEN.CA.GOV/AUTISM

The Honorable Arnold Schwarzenegger
Governor of California

The Honorable Don Perata
President pro Tempore of the Senate
and Members of the Senate

The Honorable Dick Ackerman
Senate Minority Leader

The Honorable Fabian Núñez
Speaker of the Assembly
and Members of the Assembly

The Honorable Michael Villines
Assembly Minority Leader

Dear Governor and Members of the Legislature:

We are pleased to submit "The California Legislative Blue Ribbon Commission on Autism Report: An Opportunity to Achieve Real Change for Californians with Autism Spectrum Disorders." The report details the findings and recommendations of the California Legislative Blue Ribbon Commission on Autism, pursuant to Senate Concurrent Resolution 51 (Perata), Resolution Chapter 124, Statutes of 2005.

The Commission was established to study and investigate the early identification and intervention of autism spectrum disorders (ASD); gaps in programs and services related to the education and treatment of children, adolescents, transitional youth, and adults with ASD; and the planning required to address the "aging out" of children who comprise the current autism epidemic.

This report is the product of a year-long process that involved numerous stakeholders throughout the state. In addition to three public hearings convened by the Commission, individual members and staff of the Commission participated in nine day-long task force meetings and 11 town hall meetings across the state. The Commission is most grateful for the important assistance and contributions provided by the caring individuals who participated in this work during the past year.

The findings of this report underscore the importance of ASD as an important public health issue. Further, the Commission's analysis emphasizes the complex nature of these disorders. Individuals with ASD frequently require numerous medical, behavioral, and educational interventions, and therefore require knowledge of and access to multiple and complex systems of care. Thus, although this report is focused on ASD, the Commission believes that its recommendations can be of potential benefit to a broad array of Californians who face challenges with other disabilities and special needs.

The Commission is most appreciative that Senate Concurrent Resolution 55 (Perata), Resolution Chapter 127, Statutes of 2007, extends the Commission's authorization to act until November 30, 2008. Further, on behalf of Californians with ASD and their families, the Commission stands ready to assist the Governor and Legislature in the implementation of these recommendations.

Sincerely,

Senator Darrell Steinberg
Commission Chair

Dr. Barbara Firestone
Commission Vice Chair

Contents

Executive Summary 1

CHAPTER 1 Introduction 7

CHAPTER 2 Building Models of Integrated, Comprehensive Services for Early Identification and Intervention 19

CHAPTER 3 Ensuring Appropriate and Equitable Coverage for ASD by Private Health Plans and Insurers 29

CHAPTER 4 The ASD Public Health Crisis: Improving Access to Services and Navigating Complex Systems of Care 37

CHAPTER 5 Preparing Teachers and Other School-Based Personnel to Educate Children With ASD 45

CHAPTER 6 Resolving Service Disputes Effectively and Equitably 53

CHAPTER 7 Designing New Employment and Housing Strategies for Individuals With ASD 61

CHAPTER 8 Increasing Awareness and Knowledge of ASD Among Law Enforcement Officers and Other First Responders 65

CHAPTER 9 Conclusions and Next Steps 67

APPENDICES 71

NOTES 85

Acknowledgments

The California Legislative Blue Ribbon Commission on Autism gratefully acknowledges the leadership of Senate President pro Tempore Don Perata who, with the support of Assembly Speaker Fabian Núñez, authored and spearheaded the legislation that established the Commission. The commitment of Senator Perata and Speaker Núñez to individuals with developmental disabilities and other special needs was crucial to the strong legislative bipartisan support for establishing the Commission.

The Commission would like to give special thanks to the following individuals who served as staff of the Commission and whose contributions of time, energy, expertise, and dedication were invaluable to the Commission's work and production of this report:

- Sue North, Executive Director of the Commission, Chief Consultant to the Senate Human Services Committee, staff to the Task Force on Transitional Services and Supports, and contributing writer to the report
- Dr. Lou Vismara, Policy Consultant to President pro Tempore Don Perata; parent of a 14-year old son, Mark, who has autism; staff to the Task Force on Early Identification and Intervention; and contributing writer to the report
- Harriet Levy, Assistant Consultant to the Commission, staff to the Task Force on Education and Professional Development, and contributing writer to the report
- Jody Martin, Consultant at the Senate Office of Research and managing editor and contributing writer to the report
- Myesha Jackson, Legislative Director for Senator Darrell Steinberg
- Michelle Caballero, Executive Assistant of the Commission
- Ginny Puddefoot, Senior Research and Policy Specialist at the California Research Bureau of the California State Library

The Commission would also like to acknowledge and thank the many Californians across the state who participated in the Commission's hearings, task force and town hall meetings, and other venues to provide invaluable information, support, and insights about issues and needs affecting Californians with autism spectrum disorders. The dedication, passion, commitment, and vision of these individuals greatly enriched the Commission's discussion and the content of this report.

The Commission wishes to pay tribute to Californians with autism spectrum disorders, and their families and friends. Throughout its work, the Commission was inspired by their courage in confronting the challenges presented by autism and by their tenacity and commitment in finding the pathways to hope. The Commission pledges its continued dedication to improving the lives of Californians with autism spectrum disorders and their families.

Executive Summary

The dramatic growth in the number of children affected by autism spectrum disorders (ASD) now constitutes a public health crisis. Throughout the state of California, families and systems of care are struggling to meet the needs of individuals with ASD across their life span. The California Legislative Blue Ribbon Commission on Autism was established to identify the gaps in programs, services, and funding for ASD and develop recommendations to the State Legislature and Governor Arnold Schwarzenegger to address these gaps.

Pursuant to Senate Concurrent Resolution 51 (Perata), Resolution Chapter 124, Statutes of 2005, the California Legislative Blue Ribbon Commission on Autism presents this report of its findings and recommendations to close the gaps in programs, services, and funding for Californians with ASD and their families.

To fulfill its charge, the Commission established a statewide forum and process using task forces, town hall meetings, and other approaches to obtain input from families and other ASD stakeholders. The Commission's findings and recommendations reflect significant gaps that warrant action and could serve as a roadmap for further change. Creating a seamless system of comprehensive programs and services for ASD would require a significant investment of resources that are not currently available. Therefore, many of the Commission's recommendations promote the development of successful models through demonstration projects and other targeted efforts so that effective approaches can be expanded when additional resources are available.

Summary of Findings

The Commission identified specific issues that currently impose serious barriers and challenges to the health and well-being of individuals with ASD and to the support needed by their families. These specific findings and gaps are presented and described in detail within each of the subsequent chapters. Each chapter also contains pertinent background information and proposed goals and objectives for state policy.

Many of the issues are evident for individuals with ASD and their families across their life span and involve multiple systems of care. Thus, the Commission's findings of major "overarching" gaps are summarized as follows:

1. There is a significant number of children with ASD who have not been screened, assessed, or referred to early intervention services in an appropriate and timely manner. These delays are longer and occur with more frequency in underserved populations and communities.

2. In many communities, public awareness, education, and outreach efforts on ASD programs and services must be intensified and expanded.

3. Many existing systems of care are very complex, and a significant number of families confront major barriers in accessing and navigating programs and services. Transitions across systems and programs are especially difficult for children with ASD at age three. In addition, families report problems accessing ASD services through their health insurance coverage.

4. There are many ASD programs and services that require greater coordination and integration to comprehensively and effectively serve individuals with ASD throughout their life span.

5. Many ASD programs are often categorical in nature; therefore, eligibility criteria and the types of services offered may vary across the state.

6. Many ASD programs and services could be improved by the availability of additional resources, infrastructure, and supports to meet the needs of all individuals with ASD and their families.

7. Many ASD programs and services would benefit from the availability of additional professional and paraprofessional development and training.

8. Some ASD programs that involve the public and private sectors require clarification about the roles and responsibilities of each group that provides ASD services.

9. In many regions of the state, some programs, services, and persons who are involved with and respond to specific emergencies, such as medical and public safety responders, require additional information and training on ASD.

10. Many programs that provide services to individuals with ASD and their families could benefit from additional resources and assistance to promote effective strategic planning, communication, and collaboration between service agencies and consumers and their families, and thereby also avoid contentious disputes.

11. Some highly effective programs and services for ASD should be identified, analyzed, evaluated, and replicated throughout the state.

12. Throughout the state, there is an intense need to plan for and address the impending housing, transportation, employment, and educational needs of the "tsunami" of young people with ASD who will soon transition into community settings.

Summary of Policy Recommendations

The Commission was charged with analyzing the existing gaps and providing policy recommendations that would begin to address these issues. The recommendations are related to the three key areas identified in Senate Concurrent Resolution 51:

- Early identification of ASD;
- Education and treatment of children, adolescents, transitional youth, and adults with ASD; and
- A comprehensive and integrated continuum of programs, services, and funding required to address the "aging out" of children who comprise the current autism epidemic.

The policy recommendations related to the three key areas are outlined in Chapters 2 through 8 of this report and summarized here as follows:

EARLY IDENTIFICATION AND INTERVENTION Establish a demonstration project at multiple sites that will serve as a template to expand early identification programs. The demonstration project should focus on distressed communities; ensure the timely diagnosis of and intervention for children with ASD; improve collaboration among providers; provide support to families and caregivers; establish a seamless system for service delivery between regional centers and local education agencies; and promote smooth transitions across programs for children with ASD from birth to kindergarten (Chapter 2, page 19).

HEALTH INSURANCE COVERAGE Enact legislation, regulations, and other policies to ensure appropriate and equitable coverage for ASD by private health plans and insurers (Chapter 3, page 29).

THE ASD PUBLIC HEALTH CRISIS Implement a statewide public awareness campaign on ASD linked to innovative efforts by the California Department of Public Health to improve access to and navigation of programs and services for ASD (Chapter 4, page 37).

EDUCATION OF CHILDREN WITH ASD Address the need to increase the number of teachers, paraprofessionals, and other school-based personnel trained in education of children with ASD (Chapter 5, page 45).

RESOLUTION OF SERVICE DISPUTES Empower families and local education agencies to collaborate in establishing appropriate and effective individualized education programs for children with ASD. Have the state of California conduct a comprehensive and independent review of the process for resolving service disputes and identify and promote effective dispute resolution models (Chapter 6, page 53).

NEEDS OF YOUTH AND ADULTS WITH ASD Expand postsecondary educational opportunities and establish new and effective career technical education models, including intensive support, for individuals with ASD. Expand innovative community-based approaches to supported employment, transportation, social-recreational programs, and housing for the ASD population (Chapter 7, page 61).

AWARENESS OF ASD IN EMERGENCY SITUATIONS Provide training and information on ASD to peace officers, first responders, allied judicial public agencies, and emergency response systems (Chapter 8, page 65).

Conclusions and Next Steps

The Commission urges the State Legislature and Governor Schwarzenegger to adopt these recommendations by enacting legislation the Commission will offer for the next legislative year. The ensuing legislative discussion must include a comprehensive fiscal review and analysis of current state spending on programs and services for ASD and the impact of the Commission's recommendations.

The Commission also urges state policymakers to make ASD an important public policy priority during the next three to five years. As part of an ASD public policy agenda, there should be greater coordination in planning and policy development across the state agencies that have key roles and responsibilities for helping Californians with ASD and their families.

Given the Commission's time frame, it was not feasible to address all issues identified by families and other ASD stakeholders. The following important issues warrant further analysis to identify appropriate solutions:

- There is an insufficient number of developmental pediatricians, speech and language therapists, behavioral therapists, occupational and physical therapists, psychiatrists, psychologists, neurologists, and other health care providers to provide services to individuals with ASD.
- Low-income Californians who receive health and mental health care services through the Medi-Cal Program experience serious problems locating primary care and other health care providers with ASD expertise.
- A diagnosis of autism does not entitle children and youth who are full-scope Medi-Cal eligible and under age 21 to receive specialty mental health services through county mental health plans under the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit.
- There is a need for long-term quality assurance and monitoring of the efficacy, or alternatively any specific risks, of the interventions and treatments provided to individuals with ASD.
- The needs of older adults with ASD must be addressed in a comprehensive way as the ASD population, their parents, and other caregivers for this population age.
- There is a far-reaching problem of inadequate compensation and other incentives for service providers across systems of care to serve persons with ASD and other special needs.

During the year ahead, the Commission looks forward to working with state policymakers on the recommendations and other issues identified in this report.

CHAPTER 1
Introduction

The California Legislative Blue Ribbon Commission on Autism presents this report of its findings and recommendations to the California State Legislature and Governor Arnold Schwarzenegger as an initial roadmap for state action to achieve meaningful change in the lives of Californians with autism spectrum disorders (ASD) and their families.

In 2005 the Legislature enacted Senate Concurrent Resolution 51 (Perata), Resolution Chapter 124, Statutes of 2005, authorizing the California Legislative Blue Ribbon Commission on Autism to study and investigate issues related to ASD until November 30, 2007. The resolution requires the Commission to submit at least one report of its findings and recommendations to the Legislature and the Governor by September 30, 2007. In 2007 the Legislature enacted Senate Concurrent Resolution 55 (Perata), Resolution Chapter 127, Statutes of 2007, extending the authorization of the Commission to act until November 30, 2008. Appendices A and B contain copies of each resolution.

In creating the Commission, the Legislature recognized that California requires comprehensive solutions to significantly improve services and enhance opportunities for all individuals with ASD and their families. California is in a unique position to lead the nation in developing and implementing these solutions due to its existing infrastructure of programs and services and groundbreaking scientific work and best practices guidelines on ASD.

A Public Health Crisis With Significant Challenges for California

The dramatic growth in the number of children diagnosed with ASD in California and the United States is a public health crisis that must be addressed. Autism spectrum disorders are complex neurological disorders of development that onset in early childhood. ASD includes full spectrum autism and the related disorders: Asperger's syndrome and Pervasive Developmental Disorder, Not Otherwise

Specified, as defined in the "Diagnostic and Statistical Manual of Mental Disorders, 4th edition."[1] These disorders affect the functioning of the brain to cause mild to severe difficulties, including language delays, communication problems, limited social skills, and repetitive and other unusual behaviors.

Nationally, ASD now affects an estimated one in every 150 children across all racial, ethnic, and socioeconomic backgrounds.[2] ASD is more prevalent in males and affects one in every 94 boys. The spectrum of ASD represents the fastest growing serious developmental disability in California and the nation.[3] ASD is more common than childhood cancer, juvenile diabetes, and pediatric AIDS combined.[4]

Given the absence of a comprehensive public registry for reporting ASD cases, the true number of Californians with ASD is unknown. Based on the estimated national prevalence rate of one in every 150 children, it is estimated that approximately 3,300 to 3,700 of the more than 500,000 children born in California every year will eventually be identified with ASD.[5] California faces significant challenges to identify children with ASD as early in their lives as possible and provide individuals diagnosed with ASD with the necessary programs and services.

Although the etiology of ASD is unknown, experts believe there is more than one cause for ASD.[6] Genetics appear to play a role, and there is growing scientific evidence about the role of environmental influences. Research is underway to investigate the extent genetic and environmental factors contribute to ASD. Although some have questioned how much of the growth of ASD is due to an actual increase in the prevalence of these disorders versus other changes that occurred over time resulting in increased detection and diagnosis, such as better detection techniques, increased awareness, and broadening of the ASD diagnostic category. Notwithstanding this debate, there is no question about the importance of providing services to persons with ASD throughout their lives to mitigate the impacts of ASD.

The field is in a dynamic process of assessing the efficacy of treatments for ASD. There is no known cure for these disorders. Experts agree that treatment should be tailored to address the needs of the individual, and no single intervention is best for every person with ASD. There is also widespread agreement that it is important for children with ASD to receive intensive interventions during early childhood. Research indicates that some interventions have a high degree of efficacy for treating certain symptoms of autism in some children.[7] Our understanding of the effectiveness of interventions will advance through greater use of interventions and the monitoring of outcomes. Efforts are underway to better define for the field effective interventions for ASD and specific program elements of interventions so

they can be replicated successfully in the home, at school, and in other community settings.

California Leads in Services for ASD

In many respects California is well positioned, compared to other states, to meet the service needs of individuals with ASD and their families. In 1971, autism was added to the state's Lanterman Developmental Disabilities Services Act, and under that law California provides more services to persons with ASD and their families than any other state. In 1974, California enacted legislation to specifically address the educational service needs of children with ASD. No other state has such an extensive infrastructure of community-based programs and services across multiple systems of care available to individuals with ASD and their families. Many dedicated and skilled individuals work within these systems to provide high quality services.

The state developmental services system provides treatment, habilitation, and other services to Californians with developmental disabilities so that they may lead more independent, productive, and integrated lives. Persons with full spectrum autism are eligible for services. Individuals with other forms of ASD are not eligible unless they are assessed to have impairments that constitute a substantial disability. The California Department of Developmental Services contracts with 21 regional centers across the state that coordinate, purchase, and provide community-based services for eligible consumers with developmental disabilities.

Nearly 35,000 Californians with autism are now served through the developmental services system.[8] The system now serves more persons with autism than individuals with a primary diagnosis of cerebral palsy. Roughly 85 percent of the consumers with autism are under age 22, indicating a large wave of persons with autism will enter adulthood beginning in a few years. The number of individuals with autism in the system has more than tripled since 1998 and increased more than twelvefold since 1987.[9] During the past five years, the system experienced an annual net increase of about 3,200 persons with autism. These 3,200 persons added each year represent about 50 percent of all persons added to the system statewide.[10]

California's Early Start Program provides service coordination and screening, diagnostic, assessment, and various early intervention services to children from birth up to 36 months of age who have a developmental delay or are at risk of delayed development or a developmental disability and their families. The program is

implemented in the community by the regional centers under contract with the California Department of Developmental Services. More than 40,000 California children, about 2.5 percent of children under age three, are served through the program annually.[11] It is unknown how many children served have the symptoms or diagnosis of ASD since many children do not have an official diagnosis by age three.

California's public education system is responsible for the education of children with ASD beginning at age three. Local education agencies, primarily school districts, educate many children with high-functioning ASD through regular education programs. The agencies also provide specialized educational interventions and related services to many children with ASD and other disabilities so they can benefit from a free and appropriate public education. Nearly 40,000 California preschool and school-age children with ASD between the ages of 3 and 22 now receive special education services from local education agencies.[12] During the six years between 2001 and 2007, the number of children with ASD in California's special education system increased by 183 percent, representing an average increase of more than 4,000 children each year.[13] The growth in the special education population with ASD far outpaced the 3.9 percent rate of growth in K-12 enrollment from 2000-01 to 2006-07.[14]

Pediatricians and other health care and mental health care professionals in California have an important role to provide individuals with ASD and their families with a "medical home" that provides and coordinates medical care, including services for the detection and treatment of ASD. Families may obtain assistance in covering the cost of services through their private health insurance coverage. California's mental health parity law, Assembly Bill 88 (Thomson), Chapter 534, Statutes of 1999, requires the majority of private health plans and insurers in California to provide covered individuals with coverage of health care and mental health care services for the diagnosis and medically necessary treatment of ASD. Low-income Californians who are eligible for health care and mental health care coverage through the state's Medi-Cal Program may access services for the diagnosis and medically necessary treatment of ASD through the Medi-Cal Program.

California Leads in Science, Knowledge, and Best Practices on ASD

California is one of the nation's leaders in the development of groundbreaking science, knowledge, and best practices on ASD. California is in a unique position in the country to apply lessons from this evolving body of work through the state's

infrastructure of programs, services, and systems of care to improve services for all Californians with ASD.

The California Department of Developmental Services provides leadership to promote quality services for Californians with ASD. In 2001 the department launched an Autistic Spectrum Disorders Initiative to establish policy and best practices in assessment and intervention, and to establish public and private partnerships to address the needs of persons with ASD. The initiative yielded the 2002 report "Autistic Spectrum Disorders: Best Practice Guidelines for Screening, Diagnosis, and Assessment," and the ASD Learning Collaborative Project to promote use of the guidelines across the state. In 2006 the department initiated the Autistic Spectrum Disorders: Guidelines for Effective Interventions Project to examine the quality of interventions used for individuals with ASD, in conjunction with a related National Standards Project conducted by the National Autism Center. The two projects are anticipated to produce findings by June 2008. The department also plans to publish a guide on effective collaboration between agencies for ASD services.

California's institutions of higher education conduct cutting-edge biomedical and clinical research on ASD; provide evidence-based diagnostic, assessment, and treatment services to patients with ASD; and share the latest evidence-based techniques through comprehensive educational and training programs for parents, health professionals, educators, researchers, students, and others working in the field. State-of-the-art work on ASD is conducted across the University of California system by the Medical Investigation of Neurodevelopmental Disorders (M.I.N.D.) Institute at the University of California, Davis; Semel Institute and Resnick Neuropsychiatric Hospital at the University of California, Los Angeles; For OC Kids Autism Center, associated with the University of California, Irvine; Autism Research Program at the University of California, San Diego; Pervasive Developmental Disorders Clinic at the University of California, San Francisco; and Koegel Autism Research Center at the University of California, Santa Barbara.

Within the California State University system, several of the universities include training on ASD as part of preparation and/or professional development programs for teachers and other school personnel. To varying extents such training is happening at the universities at Fresno, Los Angeles, San Diego, and Stanislaus. Within the California Community Colleges system, there is tremendous potential to expand innovative career training programs for young adults with ASD. At this time, only one community college, Taft Community College, has a fully developed campus-based career-training program for the ASD population.

California recognizes the importance of further action to help public and nonpublic schools better serve students with ASD and their families. Assembly Bill 2513 (Pavley), Chapter 783, Statutes of 2006, requires the state superintendent of public instruction to develop recommendations for (1) creation of a statewide clearinghouse on research-based educational practices to support children with ASD; (2) informing schools about effective educational practices for ASD and outreach services available to children with ASD and their families; and (3) the need for a technical assistance program to assist schools with teacher training and development of effective programs on ASD. The superintendent convened an Autism Advisory Committee for this purpose to submit recommendations to the Legislature by November 1, 2007.

Despite Progress, Significant Gaps Remain

California can be proud of its ongoing investment and commitment to improve the lives of Californians with ASD. At the same time the state must recognize that its work has just begun to address the needs of this population.

Notwithstanding the beneficial programs and services that many Californians with ASD now receive, on the whole, California's systems of care are struggling with inadequate fiscal and other resources to serve individuals with ASD. The systems are overwhelmed by the magnitude of this growing population given the complexity, intensity, and economic costs of services individuals with ASD need throughout their lives. Across the state, families and representatives of service systems report there are significant gaps in programs, services, and funding for Californians with ASD and their families. There is an urgent need for comprehensive planning, preparation, and resources across the systems to meet the full range of service needs that individuals with ASD and their families have throughout their lives.

There are gaps for young children and school-age children in the detection of ASD and in children's assessment, education, and treatment provided through regional centers, local education agencies, and families' private health insurance. An urgent concern is the lack of education and training on evidence-based best practices and promising approaches for ASD detection, education, and treatment to empower parents, educators, pediatricians, speech and language therapists, behavior therapists, and other professionals and paraprofessionals to best serve this population. Evidence-based practices and cutting-edge research findings are utilized by specialists in ASD at leading medical centers and comprehensive educational and other programs. However, this information may not be widely available to or used

by the hands-on service providers who help most persons with ASD in the home, at school, and in other community settings.

There are problems involving access to services, including limited, inconsistent, and poorly coordinated services across systems of care. Systems have different eligibility, assessment, and service requirements and practices, which can be difficult for families to navigate as they try to obtain comprehensive care. Families can experience difficult transitions across systems and programs when children turn age three. Families also report difficulties accessing ASD services through their private health insurance coverage. Service agencies may provide conflicting information and decisions about an individual's needs. While systems are supposed to collaborate and plan ahead for achieving successful long-term outcomes for individuals across their life span, especially during times of major transition, such collaborative planning frequently is inadequate or absent. Consequently, instead of effectively helping to prevent crises, systems as a whole are more responsive during a crisis. Often parents disagree with service agencies about programs and services that children should receive. Disputes between families and service agencies can be costly and time consuming to resolve through formal administrative and other legal means. Many families lack resources to pursue their concerns.

There are gaps in programs and services for adults with ASD. Existing programs and services across the systems of care must be expanded and reformulated to meet the unique needs of this population, particularly in light of the large number of persons with ASD who will enter adulthood in upcoming years. The broad array of community services available to the public and the traditional models of service available to persons with disabilities within the developmental services system, educational system, and other support systems are not designed specifically to meet service needs of the ASD population. Developing new and appropriate models of service for persons with ASD across the systems is critically important to ensure that this population is not a forgotten group in society.

The gaps are often greatest for families and communities that are already impacted by challenges such as low socioeconomic status, limited services in rural areas and distressed communities, cultural and language differences, and other barriers. A family facing such challenges is especially unprepared for the personal and economic crises involved in supporting a child with ASD and often lacks the resources for strong advocacy to obtain what they need. Needs of underserved populations must be met to ensure that no individuals, families, and communities are left behind in the progress made on ASD.

The Commission Is Charged With Examining Gaps in Programs, Services, and Funding for ASD

The Legislature responded to reports about gaps in programs, services, and funding for ASD by charging the California Legislative Blue Ribbon Commission on Autism with the following three prime objectives:

1. Identify gaps in programs, services, and funding related to the early identification of ASD and provide recommendations to close the identified gaps

2. Identify gaps in programs and services related to the education and treatment of children, adolescents, transitional youth, and adults with ASD

3. Make recommendations for the planning of a comprehensive and integrated continuum of programs, services, and funding that will be required to address the "aging out" of children who comprise the current autism epidemic.

There are several reasons that these three areas—early identification, education and treatment, and comprehensive services for adults—were identified as most critical for study. Each area is extremely important to improving the lives of and optimizing successful opportunities and outcomes for individuals with ASD across their life span and for their families. There are major gaps in the ability of individuals with ASD and their families to access comprehensive and efficacious services across each of these areas, and some families and communities are especially underserved. Improvements across the areas that benefit Californians with ASD would also be of appreciable benefit to Californians with other disabilities and special needs who are served through the same systems of care.

Finally, across all of these areas there are important fiscal implications for families, service systems, and the state of California, since the costs of providing specialized services for ASD are escalating rapidly with the growth of the population. For that reason, it is imperative to meet this population's lifelong service needs through strategies that are also cost effective and efficient. We know that service needs and costs are greater later in life when a person's early developmental needs are not addressed effectively through early intervention. Providing effective services across the life span—from early childhood through adulthood—is critical to maximizing successful outcomes for Californians with ASD and the cost effectiveness of society's investment for this population.

Addressing the Gaps in the Context of Fiscal Constraints

The state of California is facing significant fiscal constraints now and in the foreseeable future. This is the context in which state policymakers will receive the Commission's recommendations. Therefore, the Commission approached its work by trying to balance the need to close the most urgent gaps with the reality of limited resources in the immediate years ahead. The Commission embraced three key strategies to strike this balance when developing the final recommendations in this report.

First, recommendations reflect the most pressing issues and gaps identified by families and other ASD stakeholders. Second, recommendations promote the development of successful models through demonstration projects and other targeted efforts so that effective approaches can be expanded when additional resources are available. Third, recommendations promote greater awareness and use of best practices and promising approaches that have demonstrated efficacy or the potential for success in serving individuals with ASD. These strategies are intended to ensure that the state can act upon the Commission's recommendations that call for increased investments and make real progress in the next few years. In addition, the Commission believes there is tremendous potential for current efforts and resources now spent across systems of care to include a greater focus on ASD. For example, there are opportunities to include a focus on ASD as part of locally-designed early developmental screening and referral programs and other family-focused projects funded through a combination of sources, including local First Five Commissions (Proposition 10), counties, and other sources. The state and local partners can act now on ASD, and also maximize the investment of new resources for ASD, by building on and leveraging existing efforts to the extent possible.

The Commission recognizes that many of the gaps in programs and services for Californians with ASD are clearly related to funding levels across the systems of care. Closing these gaps will no doubt require a significant investment of resources into these systems. The Commission acknowledges that increased funding for programs and services for the ASD population is a critical need. However, given the state's current fiscal circumstances, it is imperative that these allocations be linked to demonstrable outcomes and effective public policy. Although a detailed analysis and discussion of these funding gaps was considered beyond the scope of the Commission's initial report, the Commission recommends that these fiscal issues be addressed in the near future to effectively deal with the ASD public health crisis.

Commission Membership and Process

The 16-member Commission brings a wealth of expertise in ASD and related key fields to study the issues: six members are parents of individuals with ASD, two are medical professionals, four are education experts, two are experts on regional center services, three are business leaders, two are legal experts, and three are leaders in government and public policy. The Commission also reflects a diversity of perspectives across geographic, ethnic, cultural, and gender backgrounds. Members of the Commission, listed below, were appointed by Senate President pro Tempore Don Perata and Assembly Speaker Fabian Núñez. Brief biographies of the members are presented in Appendix C.

Senator Darrell Steinberg, Commission Chair
Barbara Firestone, Ph.D., Commission Vice Chair
Cindy Asner
Magdalena Beltran-del Olmo
Stephen Beneto
Maureen O'Leary Burness
Rudy Castruita, Ed.D.
David Feinberg, M.D.
Ronald Huff, Ph.D.
David Kears
Lynn Koegel, Ph.D.
Areva Martin, Esq.
Rick Rollens
Kenneth Simril
Eleni Tsakopoulos-Kounalakis
Albert Wang, M.D.

To fulfill its charge, the Commission established a statewide forum and process to obtain the input of California families and other stakeholders affected by ASD, including health professionals, educators, regional centers, organizations that represent or work with children and families, relevant state agencies, and other service agencies and providers that have direct experience with these disorders. This report of the Commission's findings and recommendations is a response to the problems, themes, stories, perspectives, hopes, and ideas that these stakeholders expressed throughout the process.

The Commission used a multifaceted approach to obtain stakeholders' input. Between September 2006 and September 2007, the Commission convened three public hearings. The Commission also created three task forces with broad representation to conduct focused study and investigation of specific issues. The Task Force on Early Identification and Intervention focused on early identification and intervention for young children with ASD from birth through age five. The Task Force on Education and Professional Development focused on education and treatment of children and youth with ASD from ages 3 to 22 who receive special education services from local education agencies. The Task Force on Transitional Services and Supports focused on needs of adults with ASD and adolescents who are transitioning into adulthood. Appendices D, E, and F contain a list of members of each task force. Each task force conducted meetings in various parts of the state to identify and prioritize issues and recommendations for the Commission's consideration.

The Commission used the priorities and recommendations identified by the task forces as the basis for additional public discussions at several town hall meetings conducted across the state in Fremont, Fresno, Los Angeles, Riverside, Oakland, and Petaluma. In the future, the Commission intends to hold additional town hall meetings and other discussions in more communities as part of an ongoing public input process.

The breadth and depth of issues identified through the public engagement process yielded a broad compendium of recommendations from which the Commission developed consensus for a first set of policy priorities for the 2008 legislative session in California.

Three broad points regarding these recommendations need to be emphasized:

1. The Commission believes that adoption and implementation of the recommendations will make a positive, appreciable difference in the lives of individuals with ASD, and their families and communities, and build a strong foundation for future work.

2. Closing the gaps identified in this report may require actions, at all levels of government and across public and private sector entities. The Commission hopes this report serves as a springboard for further collaborative discussions and efforts to address the needs of Californians with ASD.

3. Many issues and gaps related to serving Californians with ASD are systemic challenges across service systems that affect a broader population of children and adults with disabilities and other special needs. Addressing these systemic challenges would benefit the broader populations served by the systems.

Organization of this Report

Chapters 2 through 8 present the Commission's findings of gaps in programs, services, and funding for ASD and recommendations for initial state policy to close the gaps.

Chapter 2 discusses the need to ensure early identification of ASD and children's access to effective interventions through seamless systems of care.

Chapter 3 covers the need to ensure appropriate and equitable private health insurance coverage for the detection and treatment of ASD.

Chapter 4 addresses the need for a comprehensive, state-led public health initiative and infrastructure to respond to the ASD public health crisis.

Chapter 5 deals with the preparation of educators and other school-based personnel to educate children with ASD.

Chapter 6 describes issues related to the resolution of ASD-related service disputes between families and service agencies.

Chapter 7 highlights the need for new employment and housing strategies for the ASD population.

Chapter 8 stresses the need for improved awareness and knowledge of ASD among law enforcement officers and other first responders.

Chapter 9 provides conclusions and next steps for the Commission's work.

CHAPTER 2
Building Models of Integrated, Comprehensive Services for Early Identification and Intervention

Findings

- In a significant number of children, ASD is identified late in childhood or missed altogether.
- Many children diagnosed with ASD do not receive timely and appropriate intensive interventions.
- Children of low socioeconomic status, children living in rural areas, Latino children, and African American children are often diagnosed later than other children and are less likely to access early interventions.
- Existing community systems of care often do not collaborate to provide integrated, comprehensive services for children with ASD and their families.
- The medical system is overwhelmed, underfunded, and ill-prepared to deal effectively with ASD and often lacks linkages to other systems of care.
- Families often face a crisis when children with ASD reach age three and transition from the Early Start Program services provided through the regional center to the local education agency program.

Goal

- Ensure the early identification and access to seamless systems of effective intervention for children with ASD from birth to kindergarten.

Policy Recommendation

1. **Establish a demonstration project at multiple sites (including one or more sites in underserved communities), based on best practices in the field that are culturally sensitive, that will serve as a template that can be expanded and replicated to accomplish the following outcomes:**

- **Expand early identification programs, including a focus on children in socioeconomic distressed and rural areas;**
- **Ensure access to intervention in a timely manner after detection with interagency collaboration;**
- **Improve communication and sharing of information between health care providers and community-based programs, services, regional centers, and local education agencies;**
- **Collaborate with systems of care that are now working to promote early identification, developmental screening, and referral to support (for example, some counties have developed pediatric developmental screening and assessment programs to address the problem of drug-exposed infants);**
- **Provide supports to families and caregivers to promote optimum development of children with ASD in the home environment;**
- **Improve communication between the "medical home" and families;**
- **Expand resources, supports, educational training, and other opportunities for health care professionals relative to early identification and intervention; and**
- **Provide a seamless system for service delivery between regional centers and local education agencies for children with ASD from birth to kindergarten, and thereby promote smooth transitions across systems and programs for children at age three.**

2. **The state of California should enact legislation to expand developmental surveillance and screening, including screening for ASD, for children from birth to age five through the use of research-based screening tools that have been demonstrated to be standardized, reliable, valid, and accurate for children from a range of racial, ethnic, linguistic, and cultural backgrounds. Increased screening activity could be implemented through well-baby visits, public programs, such as the Early Start Program and the Child Health and Disability Prevention Program, and other settings.**

Background

Autism spectrum disorders are complex disorders with variable and fluctuating manifestations. Nevertheless, progress made in early detection techniques now allows for earlier diagnosis of these disorders, frequently before a child's second or third year of life.[15] Typically full spectrum autism can be diagnosed earlier than

other less severe forms of ASD, such as Asperger's syndrome and Pervasive Developmental Disorder, Not Otherwise Specified.

Children with ASD do not follow the typical patterns of child development; rather, ASD is marked by the absence of ordinary skills that would be expected according to the major developmental milestones. Research has identified a number of developmental "red flags" that can indicate ASD in young children: poor eye contact; reduced responsive smiling; diminished babbling; reduced social responsivity; difficulty with language development, play, and initiating or sustaining social interaction; failure to respond to their names; and a lack of joint attention.[16]

Despite these advances it is estimated that in the United States only 50 percent of children with ASD are diagnosed before they enter kindergarten, which is typically at age five.[17] Studies also show that some populations of children are more likely to be diagnosed later than other children, in some cases up to one or two years later. There is evidence that late diagnosis occurs more frequently among children of low socioeconomic status, children living in rural communities, Latino children, and African American children.[18]

Many disabilities often go undetected until children enter school. In the United States, an estimated 17 percent of children have a developmental or behavioral disability. However, it is estimated that less than 50 percent of these children are identified as having a disability before they enter school.[19]

Developmental Screening Is Crucial

Current best practices indicate that effectively screening all children across a wide range of developmental domains is crucial to the early detection of children with ASD.

Both the American Academy of Pediatrics and the American Academy of Neurology recommend that developmental surveillance, using validated screening instruments, should occur at all well-child visits for children from birth through school-age.[20] Several general developmental screening tools exist. Some tools use information provided by parents and others include direct child observation. Some recommended developmental screening tools that rely on parent information include Parent's Evaluation of Developmental Status (PEDS), Ages & Stages Questionnaires (ASQ), and PEDS-Developmental Milestones (PEDS-DM).[21] Experts indicate that "good screens make a correct decision at least 70 percent to 80 percent of the time."[22] Screening instruments may be used by trained professionals or paraprofessionals in the primary care setting or in other community-based settings, such as schools, child care and early childhood programs, and other settings. [23] These screenings are intended to identify children who should receive further evaluation for ASD and/or other developmental problems.

Serious Developmental Delays Are Frequently Missed

Pediatricians have a critical role in the detection of children with ASD and other developmental problems. They are dedicated professionals who strive to effectively serve children and families, including the most vulnerable populations. However, they have a high demand for services, receive limited rates of payment, and face other serious constraints. The Commission recognizes that the state can and should do more to support the role of pediatricians, particularly with respect to developmental screening.

Research confirms that there are serious gaps in the detection of children with significant developmental problems. For example, many parents report not having adequate consultation time with their pediatrician. In one study, 37 percent of parents of young children reported concerns about their child's learning, behavior, or development, but only 18 percent of parents were able to discuss these concerns with their pediatrician.[24] Not infrequently, health care providers may dismiss parental concerns as "just something that is normal and takes more time," thereby frustrating the family and delaying potentially beneficial interventions.

Research also has established that the pediatrician's appraisal of a child's developmental status may be inaccurate without the use of a standardized developmental screening tool. Surveys of pediatricians and parents show that most pediatricians do not use screening tools to assess children for developmental problems. According to a 2002 survey by the American Academy of Pediatrics, over 70 percent of pediatricians reported using only clinical observation (without a

screening instrument) to identify children with developmental delays. Only 23 percent of pediatricians reported using a standardized developmental screening tool.[25]

Many pediatricians report being inadequately trained to use developmental screening tools, lacking time and reimbursement to conduct the screening and assessment, and lacking services to refer children for assessment and treatment.[26] According to one study that reported findings from the 2000 National Survey on Early Childhood Health: "Only 57 percent of children age 10 to 35 months ever received developmental screening by their primary care provider."[27] This study also reported that pediatricians fail to identify and subsequently refer in a timely manner about 60 to 80 percent of children with developmental delays.[28]

Studies show that parents are often first to notice unusual behaviors in their child, and they are usually correct in their concerns.[29] It is reported that parental concerns detect about three-fourths of children with disabilities.[30]

Best Practice Guidelines for Detection of ASD

Effective child-focused questionnaires (screening tools) are available to evaluate children between 18 to 24 months of age for signs of ASD. Experts caution that ASD screening tools do not identify all children with ASD, and in some cases detect possible signs of ASD that are not substantiated by further evaluation.[31] Researchers continue to refine these tools, as well as other diagnostic procedures, such as early language development, facial processing, and eye-tracking movements, to improve their accuracy and implementation, including their sensitivity for use among children of different racial and ethnic groups.[32]

The American Academy of Pediatrics recommends that a targeted screening tool for ASD be administered to all children at the 18-month visit.[33] The 2002 California Department of Developmental Services' publication, "ASD Best Practice Guidelines for Screening, Diagnosis, and Assessment," recommends screening for ASD at both the 18-month and 24-month visits. The guidelines recommend use of the following ASD screening tools in primary care practice: the Stage 2—Pervasive Developmental Disorders Screening Test (PDDST-II), the Modified Checklist for Autism in Toddlers (M-CHAT), the Checklist for Autism in Toddlers (CHAT), and the Screening Tool for

Autism in Two-Year-Olds (STAT). The guidelines indicate that "most screening instruments appropriate for ASD are brief and can be completed in the [primary care office] waiting room."[34]

Currently ASD can be diagnosed only by a comprehensive clinical evaluation performed by a competent and licensed provider. The evidence-based best practices for early detection of ASD are described in "ASD Best Practice Guidelines for Screening, Diagnosis, and Assessment." The recommendations are intended for parents, health care professionals, regional centers, local education agencies, and others working in the ASD field.

Once a child is identified through screening as having indicators of ASD, the child is referred for a comprehensive diagnostic ASD evaluation. Since there are no medical tests for ASD, diagnosis involves a series of diagnostic evaluations across multiple domains of functioning to differentiate ASD from other disorders. Evaluations are necessary to provide an initial diagnosis of the disorder and to detect changes in a child's condition over time. Experts indicate that many evaluations should be conducted annually or more frequently depending on the child's profile. Evaluations are conducted by a clinical specialist or a multidisciplinary team of specialists with expertise in ASD. According to Dr. Sally Rogers, an ASD specialist at the M.I.N.D. Institute at the University of California, Davis, for most children the ASD evaluation typically includes a medical exam and an exam by a psychologist, speech pathologist, and an occupational therapist. Other types of evaluations may be necessary based upon an individual's symptoms and circumstances.

Families and other observers indicate that it can be difficult for a family to obtain diagnostic services for ASD. The Commission received numerous anecdotal reports indicating a pervasive lack of providers with expertise to conduct these evaluations. Thus, even after children are suspected of having ASD, a long delay may occur before interventions can be implemented, thus missing critical opportunities for better long-term outcomes.

California Shows Progress in Early Identification of ASD

Many Californians with ASD who are now receiving services through the developmental services system and the special education system entered these systems by age five. During the past few years, children with ASD have been referred for services at younger ages than in the past, indicating that California is making progress towards better early detection.

More than half of the pupils with ASD who received special education services in December 2005 had their initial individualized education program by age three; more than three-fourths of the pupils had their initial individualized education program by age five.[35] Over one-third of all individuals with autism who were served by regional centers in December 2006 had entered the developmental services system by age three; roughly two-thirds had entered the system by age five.[36] While the age of entry into these systems isn't the age at which children received a diagnosis, it provides some indication of the approximate time frame for diagnosis.

Problematic Transition from Regional Center to Local Education Agency Programs for Children at Age Three

Families often face a crisis when children with ASD reach age three and transition from the Early Start Program services provided through the regional center to the local education agency program. Children may still continue to receive some services from the regional center if they meet the eligibility criteria under the state Lanterman Act, but children's educational and related services are the responsibility of the local education agency from ages three to 22.

In many cases this transition to the local education agency program occurs either at the time the child is undergoing the diagnostic and assessment process or shortly after a child has received an ASD diagnosis and reached a stable level of services through the regional center. The transition may occur without appropriate planning, case management, and communication, and therefore cause disruptions in evaluations and effective interventions during a critical period in early child development. There may be a gap in services between the end of a child's Early Start services plan and the development of the child's individualized education program. The local education agency may require a separate diagnostic evaluation as part of its educational programming assessment, which is different from the assessment process of the regional center. The transition may also cause the child to lose access to services and particular service providers, since regional center and local education agency programs may not offer the same or comparable services or service providers. Some schools, especially those in rural areas, may have very limited access to service providers.

Because some interventions for young children with ASD, particularly for children between the ages of three and five, cannot be clearly classified as being either developmental/adaptive or educational services, some regional centers and local education agencies have quarreled about who should be responsible for providing

these services. While service agencies wrestle over these financial issues, children and families may be without needed services.

The Commission received testimony that, in some regions, regional centers and local education agencies have developed voluntary collaborative agreements that clearly specify each agency's responsibility for ASD services. According to some parents and representatives of service agencies, these collaborative agreements have improved service delivery and increased parental satisfaction. It is clear there is a need for greater collaboration and services coordination among local education agencies and regional centers regarding young children, especially during age three to five. There is also a broader need to increase organizational support, infrastructure development, community outreach, professional development, and integration of services across multiple systems of care for appropriate early identification and intervention for children with ASD from birth to age five. Therefore, the Commission recommends that California establish and fund a demonstration project at multiple sites to build models of seamless service delivery between regional centers and school districts for children with ASD from birth to kindergarten.

Critical Window of Opportunity for Early Intervention

Early identification and intervention for ASD is critical for children to reach their full potential and reduce their level of disability and dependence. Although the outcomes of interventions and treatment for ASD vary with each child, there is widespread agreement in the field based on a large body of research that it is important for children with ASD to receive intensive interventions during early childhood.

Generally, research shows that some children with ASD who receive intensive interventions early in life may have reduced symptoms, improved functioning, and better outcomes. There is evidence that some interventions have a high degree of efficacy for treating certain symptoms of ASD in some children.[37] It is not yet clear which children with ASD are most likely to benefit from intensive early interventions. Research suggests that benefits of interventions diminish as children get older, indicating that there is a critical window of opportunity for early intervention.[38]

Dr. Catherine Lord, a leading ASD specialist, reported in one multistate longitudinal study that 35 to 45 percent of children with ASD who received early intervention could speak fluently by age nine and that only 9 percent of children remained

nonverbal. In addition, 5 percent of children no longer had symptoms of ASD, while an additional 20 percent of children exhibited signs of ASD but attended regular education classrooms.[39]

In 2004 the federal Centers for Disease Control and Prevention reported that "children with autism identified early and enrolled in early intervention programs show significant improvements in their language, cognitive, social, and motor skills, as well as in their future educational placement."[40] Another report published by the National Institutes of Health concluded that "evidence over the last 15 years indicates that intensive early intervention in optimal educational settings for at least two years during the preschool years results in improved outcomes in most young children with ASD."[41]

Early Intervention as a Cost-Effective Approach

Children with ASD who have improved functioning as a result of early intervention services may have less intensive and costly service needs for the rest of their lives, thereby reducing hardships on families and costs for systems of care to serve these individuals during adulthood. For this reason, investments in early identification and intervention services are considered an important, cost-effective approach for society.

One study published in 2006 attempted to document the total costs of autism to U.S. society. The study reported that "it can cost society about $3.2 million to care for a person with autism over his or her lifetime and about $35 billion (in direct medical, direct nonmedical, and lost productivity costs) to care for all individuals with autism over all of their lifetimes." However, the study also indicated that the total annual costs "could range from $13 billion to $76 billion" depending on underlying assumptions, and that "these are highly conservative estimates" of the true societal costs because certain types of costs, such as some family out-of-pocket expenses, are not included in the estimates.[42]

Due to the challenges of cost-benefit modeling, there is limited analysis of the potential cost avoidance to society from initial investments in early intervention services for children with ASD. One study published in 1998 concluded, based on costs from Pennsylvania and assumptions of providing three years of intensive intervention to children with ASD between the age of two and school entry, that significant cost avoidance may be possible with "early intensive behavioral intervention," a specific type of intervention that uses principles of applied behavior analysis that have demonstrated efficacy with many children with ASD.[43] Another

study published in 2006 showed similar conclusions about the likely cost effectiveness of a potential expansion of intensive behavioral services for autistic children in Ontario, Canada.[44]

CHAPTER 3
Ensuring Appropriate and Equitable Coverage for ASD by Private Health Plans and Insurers

Findings

- Coverage of health care, behavioral, and psychotherapeutic services for ASD is limited, inconsistent, or excluded altogether by private health plans and insurers.
- The roles and responsibilities of health plans and insurers for ASD services are not well defined.
- Frequently there is lack of consensus about the medical necessity of services for individuals with ASD.
- When health plans and insurers contract (carve out) behavioral health services, there is often fragmentation and/or denial of services, leaving families with lost time and no services.
- Health plans and insurers do not consistently provide access to professionals with adequate training and expertise in ASD.

Goal

- Ensure appropriate and equitable coverage by private health plans and insurers for the diagnosis and medically necessary treatment of individuals with ASD, as is intended by California's mental health parity law.

Policy Recommendations

1. **The state of California should enact legislation, regulations, and other policies to ensure that:**

    - **All health plans and insurers treat ASD as a neurological medical condition (brain-based disorder) and provide the same coverage as afforded to other medical conditions such as stroke and other neurological disorders;**

- **All health plans and insurers provide a full range of medically necessary services including, but not limited to, assessment, behavioral, psychotherapeutic, psychopharmacological, speech therapy, and physical and occupational therapy services for ASD; and**
- **All health plans and insurers may not use the diagnosis of ASD as an exclusionary clause to withhold coverage, benefits, services, and interventions.**

2. **The state of California should enact legislation to:**

- **Establish an Autism Professional Advisory Council for the purpose of adopting evidence-based "best practices" guidelines for the medical evaluation and treatment of ASD; and**
- **Ensure that the Department of Managed Health Care and Department of Insurance hold all private health plans and insurers accountable for compliance with those guidelines.**

Background

Effective in 2000, California's mental health parity law, Assembly Bill 88 (Thomson), Chapter 534, Statutes of 1999, requires the majority of private health care service plans and health insurers in California to provide coverage for the diagnosis and medically necessary treatment of autism and pervasive developmental disorders, as well as other designated mental health disorders, under the same terms and conditions applied to other medical conditions.[45] As a result of this law, health plans and insurers now share major responsibilities for the evaluation and ongoing medical treatment of Californians with ASD. Despite the intent of the law, however, there are some significant issues regarding the health coverage provided to individuals with ASD.

The 2007 report by the California Department of Managed Health Care, "Mental Health Parity in California," provides an assessment of the implementation of the mental health parity law. [46] This report is based on a 2005 survey of the seven large health plans that collectively provide coverage to approximately 16 million consumers, or 85 percent of California's commercial managed care population. The report concludes that the major challenge related to health coverage of autism is "a lack of clarity regarding the distribution of responsibilities among [health] plans, regional centers, and school systems for the diagnosis and treatment of children with

autism-related disorders." The report indicates that there is some confusion among plans about their relative responsibilities compared to public sector entities. Some plans surveyed were found to "encourage" enrollees to seek services from regional centers and local education agencies.

While providing information about public sector services would be appropriate under certain circumstances, it would be a violation of the mental health parity law for a plan to refer enrollees to the public sector for services that are within the plan's responsibility. According to the report, "the written policy of one plan surveyed stated, 'The *cornerstone* (emphasis added) of service access and provision throughout the life span of a member with autism and related pervasive developmental disorders are the regional centers or Early Intervention Centers. Children under age of three and individuals past school age are the *sole responsibility* (emphasis added) of the Early Intervention Centers or regional centers.'" The California Department of Managed Health Care recommended that the relevant state agencies form an interagency collaborative workgroup to better "define the respective roles, service, and financial responsibilities of health plans, regional centers, county mental health systems, and schools [to provide services for autism]."

The report also noted that health plans vary in approach to the following issues: service delivery regarding initial evaluation of children with ASD, authorization and management of prescribed therapy and medications, and authorization and management of speech-language and occupational therapy. Some plans require prior authorization for continued therapy and medical management services once a diagnosis is established. Most of the plans surveyed require parents to go through the contracted specialty behavioral health plan to obtain referrals for evaluation, medication management, and therapy, but to go to their primary care physician or the plan's nurse case-manager for speech-language and occupational therapy. The Commission is concerned that this type of fragmentation of approvals may complicate and lead to inadequate care coordination and create confusion for families and providers about the process for obtaining plan authorization for services. In general, the nature and levels of care coordination regarding mental health disorders, not just autism, is reported to vary markedly across health plans. The report also indicates there is inconsistent coverage for applied behavioral analysis, with some plans questioning the evidence base for the effectiveness of this treatment.

Denials of Coverage for ASD and Other Issues Identified by Families

Numerous families throughout the state told the Commission about problems with health coverage for ASD, indicating that coverage for services is seriously limited, inconsistent, or excluded altogether across many health plans and insurers. Many parents noted that treatment for their children with Asperger's syndrome, despite being requested by their treating physicians, was frequently denied. One parent of a child with Asperger's syndrome received the following notification: *"The Health Plan indicates that training in learning and social skills cannot be equated to treatment for a behavioral problem or mental disorder. Additionally, the Health Plan has determined that the treatment modality applied in this setting does not focus on acute symptoms but instead on long-term traits and behaviors and therefore does not meet medical necessity criteria."*

In many cases parents reported facing innumerable delays and barriers during the administration of their claims. One family noted: *"The Case Manager informed me that she would need to give me a 'code' before I could request reimbursement for out of network services. After waiting for several weeks I contacted her again and she said that it could take up to 90 days to receive the 'codes.' I think a 90-day time frame to get 'codes' is an unreasonable burden and could result in the delay of critical services."*

Families have also alleged that health plans may provide inaccurate and misleading information. These consumers indicated that the present system lacks adequate oversight and enforcement mechanisms to ensure that health plans comply with existing regulations. One parent reported: *"The health plan stated that applied behavior analysis (ABA) is experimental and hence not covered. This is especially concerning since there are three independent medical reviews (IMR) on file with the Department of Managed Health Care stating that ABA is not experimental. The plan agreed that it is not experimental only when I refused to accept that answer. I wonder why the plan has not educated their staff about IMR decisions? How many other consumers have simply accepted this answer and have had their AB 88 rights violated?"* Another parent concluded: *"In California, we must submit to arbitration and waive our rights to a jury of our peers. This shields the nefarious deeds of some insurance companies from public exposure. This cannot continue. Health insurers must be held accountable for how they treat their clients."*

The lack of qualified providers may also pose as a major barrier as indicated by this parent's testimony: *"The Case Managers seem to have limited knowledge of what services network providers offer. After I filed my appeal I asked the Case Management supervisor to help me locate an ABA provider. She simply read off the names of mental health providers in my area. She put the burden of finding out what services each provider offered on the member (me) and made no effort to assist me beyond that."*

A clinical specialist in ASD provided an expert opinion about the extent of health coverage for diagnostic evaluations and interventions recommended for individuals with ASD. This specialist indicated that insurance often covers neurological evaluations and psychiatric medical and medication evaluations, but rarely covers other evaluations, including social skills, psychological, behavioral, and occupational therapy assessments. It was also indicated that some insurers provide some coverage of speech and language therapy, but coverage for behavioral therapy, occupational therapy, and social skills training is rare. When insurance coverage is available, families can have difficulty finding providers who have the expertise and training to provide evaluations and interventions and will accept the reimbursement rate paid by the health plan or insurer.

Two reasons are commonly cited as the basis for health plan denials of services for ASD: (1) services are considered experimental, investigational, or unproven; and (2) services are considered not medically necessary.

In many cases health plans determine that services are educational interventions that are not within their responsibility to provide and such services may be provided alternatively through local education agencies or regional centers. There can be disagreement, however, about whether an intervention is an educational intervention or a medically necessary intervention. Some interventions for autism, such as speech therapy, are provided by some heath plans, local education agencies, and regional centers, which raises questions about whether an intervention is educationally necessary or medically necessary or both, and how to distinguish between health plan, local education agency, and regional center distribution of responsibilities for such services. There are no accepted guidelines in California that clearly differentiate the responsibilities of health plans, local education agencies, and regional centers regarding the diagnostic evaluations and interventions used for autism.

Health plans may deny services for ASD for reasons related to medical necessity that are at odds with medical science. For example, some plans have denied ASD interventions on the basis that ASD is a disorder of brain development that is present from birth and therefore not amenable to medical treatments or interventions. This ruling by some health plans seems to contradict the numerous and mounting scientific evidence that ASD may be associated with multiple factors, usually become evident in the second or third year of life, are frequently associated with demonstrable changes in brain function, and appear to be caused by the interactions of genetic and environmental factors.

Another reason for denial of services by some health plans is that ASD is a chronic disorder and therefore not amenable to acute treatments or cure. Such reasoning seems at odds with the coverage that health plans routinely provide for numerous other chronic illnesses (such as diabetes and congestive heart failure) that are also frequently incurable. Thus, the frequent denial of these services for ASD by some health plans may be inconsistent both with current scientific evidence as well as with the standards and approaches applied to other illnesses and medical conditions.

Guidelines, Standards, and Best Practices for ASD Interventions

Health plan denials of ASD services often do not acknowledge or reference the emerging standards of care and best practices being developed at autism centers of excellence. For example, ASD experts have now established that such interventions as speech and language, physical, and occupational therapy may be crucial for the care of some individuals with ASD. Behavioral interventions that include pivotal response therapy, applied behavioral analysis, and directed response interventions have also proven therapeutic value in the treatment of ASD. Certain medications, at times requiring the care by a child psychiatrist who is knowledgeable in autism, have also proven efficacy. A multidisciplinary team of physicians may be required to evaluate and treat the coexisting medical problems that have also been linked to ASD. It is concerning how health plans could deny services for ASD for many of the reasons stated here when coverage for ASD is mandated specifically under California's mental health parity law. This suggests an important need for the state to adopt and enforce specific evidence-based guidelines and standards for the medically necessary evaluation and treatment of ASD.

Health Insurance Mandates on ASD in Other States

California and 10 other states (Connecticut, Illinois, Iowa, Kansas, Louisiana, Maine, Montana, New Hampshire, New Jersey, and Virginia) incorporate autism coverage as a component of their mental health parity laws.[47] There is a recent and growing trend for states to enact mandates for ASD coverage specifically. To date, Georgia, Indiana, Kentucky, Maryland, New York, South Carolina, Tennessee, and Texas have laws that provide for ASD guidelines, requirements, and/or particular services that must be covered by health insurance. Some of these states also have coexisting mental health parity laws.

The ASD-specific health coverage requirements vary in each of these eight states. Indiana, South Carolina, and New York apply a broad definition of ASD that specifically includes Asperger's syndrome. Georgia, Indiana, and New York have

established that the diagnosis of ASD cannot be used to exclude or prohibit coverage of services or benefits. Georgia, New York, and Tennessee have specified that ASD must be considered a neurological disorder. Maryland, Kentucky, and Texas have identified the specific services that must be covered by health plans. Some of these states have also provided certain limitations of ASD coverage, such as placing a maximum limit (cap) on the monthly or annual benefits covered (Kentucky); or limiting the age of ASD coverage (Kentucky children 2 to 21 years; Tennessee children under 12 years; Texas children 3 to 5 years). Other states that have considered autism-specific insurance coverage legislation include Colorado, New Mexico, Oregon, Pennsylvania, and Wisconsin.

A report from the Council for Affordable Health Insurance indicated that disease-specific state insurance mandates are not only becoming increasingly popular but do not necessarily correlate with higher insurance premiums. This report also cited that California recently became one of the first states to require specific insurance coverage of pediatric asthma education and self management.[48]

Given the problems that numerous families have identified about health insurance coverage for ASD, the Commission urges California to adopt more specific insurance requirements for the coverage of ASD services.

CHAPTER 4
The ASD Public Health Crisis: Improving Access to Services and Navigating Complex Systems of Care

Findings

- ASD is a public health problem, yet the state lacks a comprehensive public health initiative and infrastructure.
- Many Californians are not adequately informed about ASD and the value and importance of early intervention and treatment.
- Individuals with ASD and their families have difficulty in accessing and navigating programs and services.
- Programs and services that serve individuals with ASD typically lack appropriate data management and information sharing systems.
- Families in underserved populations face tremendous challenges in accessing services.

Goal

- Provide all Californians with information about ASD so they can better understand the need for early detection and treatment and how to obtain programs and services. In addition, establish a public health information system and infrastructure to improve access to and navigation of programs and services for ASD.

Policy Recommendations

1. **Require the state of California to establish an ASD public health initiative to promote greater public awareness and knowledge of ASD and improve access to programs and services for ASD, with emphasis on outreach to populations and communities currently underserved.**

2. **Require the California Department of Public Health to establish a statewide infrastructure and Office of Autism Spectrum Disorders to assist consumers in accessing and navigating programs and services related to ASD. This infrastructure (such as a toll-free telephone number, Web-based technology, print materials, and other information systems) would be linked to and integrated with existing resources.**

3. **Require the California Department of Public Health to establish a statewide voluntary registry for individuals with ASD.**

4. **The state of California should fund training, technical assistance, and other support to community-based resource centers so they can inform, train, assist, and empower families, especially those in underserved communities, to access and navigate services for ASD, thereby reflecting the needs of unique communities.**

Background

The astonishing growth in the number of children diagnosed with ASD in California and the United States is a public health crisis that must be addressed. Although the reasons for the growth remain the subject of research and speculation, there is no denying that the growth has been significant, and the long-term implications are serious for individuals with ASD and their families and service systems. ASD now affects an estimated one in every 150 children in the United States across all racial, ethnic, and socioeconomic backgrounds.[49] ASD is more prevalent in males and affects one in every 94 boys. The spectrum of ASD represents the fastest growing serious developmental disability in California and the nation.[50] It is estimated that in the United States a child is diagnosed with autism every 20 minutes, and there are more than 24,000 new cases of ASD diagnosed every year.[51] There are no indications that this growth trend will change.

Families Face Major Challenges in Accessing ASD Programs and Services

As a result of the rise in reported ASD cases and subsequent media coverage, there is generally more awareness of the occurrence of ASD. However, there are still large gaps in public awareness and knowledge of ASD, including an awareness of the early signs and symptoms, the importance of early identification and intervention, and the programs and services available for diagnosis and treatment. Families

testified to the Commission that pediatricians and other primary care providers were often poorly informed and ill-equipped to address their concerns about ASD. There are major challenges affecting a family's ability to access and navigate ASD programs and services.

ASD Requires Treatment Across Multiple Disciplines

A central issue is that individuals with ASD require long-term treatment and care across multiple and complex medical disciplines. According to Dr. Sally Rogers, an ASD specialist at the M.I.N.D. Institute at the University of California, Davis, for most children an ASD evaluation typically includes a medical exam and an exam by a psychologist, speech pathologist, and an occupational therapist. Other types of evaluations may be necessary based upon an individual's symptoms and circumstances. Evaluations may be performed by specialists, such as neurologists, psychiatrists, audiologists, immunologists, gastroenterologists, and geneticists. Typically many of these professionals must remain involved in the long-term care of these children. Persons with ASD also may have other medical problems, such as allergies, autoimmune conditions, sleep disorders, chronic gastrointestinal issues, and respiratory diseases, and thus need other specialty medical services that are often unavailable.

Individuals with ASD may also require ongoing care by a wide array of other health care professionals, including speech and language, physical and occupational, and behavioral therapists. Several years of intensive speech and language therapy are often recommended for treatment of ASD.[52] Many children with ASD have difficulties with balance, coordination, and the appropriate use of fingers, hands, and other muscles. Studies have documented that, in some children, these problems can be improved or overcome with prolonged, intensive, skilled physical, behavioral, and/or occupational therapy.[53] There is also compelling evidence that many children with ASD can respond to and improve with intensive behavior modification therapy.[54] Although the exact mechanism of action is the subject of ongoing research, there is evidence of improved brain plasticity in children with autism as the result of early interventional therapy.[55] Some autism experts also opine that these interventions may actually "rewire the brain" of some children with ASD.[56] Often this therapy is provided in the home environment and may require multiple professionals working simultaneously with the child and the family for up to 40 or more hours per week. The duration of these services varies widely, but most children with ASD will require early intensive behavior intervention for a minimum of several years as well as ongoing interventions and supports throughout their

lifetimes.[57] In addition, parent education is recommended so that intervention may be ongoing throughout the child's waking hours.

Families Grapple With Emotional and Financial Strain

Another major challenge is that families often deal with tremendous emotional and financial strain. The Commission received poignant and gripping testimony from families about their personal struggles. Further, the research clearly documents greatly increased levels of stress in parents of children with ASD.[58] While each individual with ASD represents a unique situation, the diagnosis of ASD is associated with significant anguish and distress. Initially there can be a great sense of "loss and grief" as a family may perceive that its initial dreams and aspirations for their child have suddenly evaporated. Additionally, other feelings such as anger, frustration, and denial may also plunge some families into a state of emotional chaos.

Families may pay significant out-of-pocket expenses to obtain services that are not provided through regional centers, schools, or health insurance. Some families told the Commission that they incurred significant debt to pay for critical services. Some mothers have been forced to give up their jobs for the full-time obligations of providing and coordinating care for their children. Although exact statistics have not been confirmed, the Commission received frequent anecdotal testimony about the very high incidence of divorce among these parents. It was suggested that the divorce rate in these families could be as high as 80 percent.[59] Thus, it is critical that programs and services for ASD incorporate appropriate respite and emotional support for families.

Family Empowerment Is an Important Public Health Issue

Regional centers, local education agencies, county health departments, and other community-based groups strive to meet the public health challenges of autism and assist individuals and families with access to services in their communities. In some communities these organizations have formed effective community outreach partnerships with family resource and family empowerment centers. These centers not only conduct outreach and education to families with special needs, but in some cases also offer parent training and advocacy with specific issues. These centers, typically nonprofit organizations, face ongoing fiscal challenges as they struggle to operate by combining funding from multiple sources. They face an enormous task given the challenges of effective community outreach and education. Thus, their

potential to effectively partner with state and local agencies to provide information and empowerment to consumers and families appears to be unfulfilled.

Some resource centers are funded specifically to assist families with accessing Early Start Program services through regional centers, and special education services through local education agencies. The Commission was informed that these resource centers need additional training, technical assistance, and other support to provide more effective outreach and education to families regarding ASD. There are 47 Early Start Family Resource Centers in California offering parent-to-parent support and help with location and use of needed services.[60] They offer support services and resources in many languages, which may include newsletters, resource libraries, Web sites, parent-to-parent groups, sibling support groups, telephone assistance, information and referral for parents and professionals, and transition assistance when children turn age three. Centers may operate as independent sites or be based in regional centers, local education agencies, public health facilities, hospitals, or homes. In addition, 21 community-based centers receive special education funding to provide information and support to families regarding special education services. These centers include Family Empowerment Centers, Parent Training Centers, and California Community Parent Resource Centers.[61]

The Commission was told that there is great variability in the types and level of information and assistance provided to families and service providers at the local level. As one service provider noted, *"It's so frustrating not to know what we don't know."* Sometimes information is available but is not helpful. Parents with extensive educational backgrounds reported that materials can be difficult to understand and unresponsive to special circumstances, such as cultural and/or language barriers. Families may be perplexed by the sheer number of programs that they must navigate to receive services for ASD and other family needs. For example, according to a survey in the Los Angeles area, more than 40 programs could potentially provide a wide range of health, education, and social services for a family, including families of individuals with ASD.[62] When families relocate, they can be confused by the variation in local programs and services in different regions. A major gap is the lack of a statewide information system, such as a Web-based tool that could facilitate access to programs and services in every community across the state. The Commission recommends that California explore options for developing Web-based or other informational technology and outreach strategies to help families access and navigate ASD programs and services.

Socioeconomic, Cultural, and Other Factors Are Barriers to Services

The Commission received powerful testimony about pervasive and critical gaps in access to programs and services among underserved families and communities due to factors such as socioeconomic status, educational level, language barriers, lack of services in rural areas and distressed communities, and cultural and ethnic differences. Typically children in these underserved populations are identified and receive assessments and interventions later than other children, thereby missing critical intervention opportunities.

Often families of low socioeconomic status and with a low educational level are not as prepared to advocate for services. Families that have language barriers are often unable to communicate their concerns effectively. Rural areas and distressed communities often lack service providers, and transportation in these areas can be a major problem. The Central Valley and Inland Empire are reported to lack developmental pediatricians, child psychiatrists, and child neurologists. Rural counties in northern California also have shortages of providers with ASD expertise. In regions of the state, the sparse population density requires families to travel great distances to access the few available services. One parent testified to the Commission that one hour of speech therapy for her child required four hours of riding public transportation, often while her son was severely agitated and "throwing bad tantrums." In addition, cultural and ethnic traditions and other factors can foster misunderstandings about ASD and a mistrust of service systems, and thereby influence whether or not a family seeks or is responsive to outside assistance from service agencies.

A multistate survey of 200 Latino families with children with developmental disabilities indicated that 52 percent needed assistance on all items and issues measured by the Family Needs Survey/Family Support Scale.[63] A study of Philadelphia children eligible for the federal Medicaid Program reported that, on average, Caucasian children received the ASD diagnosis at 6.3 years of age, compared with 7.9 years for African American children.[64] That study also found that African American children with ASD were more likely to be misdiagnosed as having organic psychoses, mental retardation, or selective mutism.

The Need for a Comprehensive ASD Public Health Initiative and Infrastructure

Like other critical and complex public health issues, the growth in ASD warrants a comprehensive, state-led public health initiative and infrastructure to achieve the following objectives: (1) improve the understanding and management of ASD as

both a personal and public health issue for individuals with ASD and their families, policymakers, and the general public; (2) optimize the diagnosis and treatment of ASD through adoption and promotion of evidence-based "best practices" guidelines; and (3) promote collaboration and partnerships among families and the range of state and local entities that have a role in serving individuals with ASD and their families. Each of these elements is essential for California to effectively respond to the ASD crisis.

The California Department of Public Health is the appropriate state entity to address ASD from a broad population-wide public health perspective. The California Department of Developmental Services and Department of Education have primary state-level oversight for programs that serve consumers with ASD and their families; however, neither department has the resources, expertise, or mandate to lead a public health initiative.

In 2007 the California Department of Public Health was established to "prevent illness…and promote the health status of Californians through programs and policies that use population-wide interventions."[65] The department's mandated responsibilities include disease surveillance, environmental health, health promotion, prevention of chronic diseases, health information, and strategic planning. Other intended roles for the department include elevating the visibility and importance of public health issues in the policy arena, increasing accountability and requiring program effectiveness for the public health and health care purchasing functions of state government, and recruiting and retaining public health professionals who have the education and experience to protect public health and safety.

Given its mission, there is a clear and appropriate role for the California Department of Public Health to have an Office of Autism Spectrum Disorders to lead an ASD public health initiative. Specifically, the department's emphases on environmental health, genetic diseases, information technology, health information, and strategic planning are key elements in addressing the ASD crisis. The department is also well suited to spearhead a multifaceted, statewide public information campaign on ASD. Public information campaigns have proven valuable and effective with other public health issues, such as tobacco cessation efforts, early cancer detection and treatment, and perinatal childhood development. The department is also well positioned to monitor, assess, and translate important neurobiological and biomedical advances and other scientific breakthroughs rapidly occurring in ASD research. Neither the California Department of Developmental Services nor the Department of Education has resources for this function. Both departments have an important need to keep

informed of research findings for application through ASD programs and services and ongoing planning and policy development. As the scientific community learns more about ASD, it is critically important that this information be used to improve ASD programs and services and inform future state legislation and policy development.

Establishing an Office of Autism Spectrum Disorders within the department would be consistent with the creation of other targeted programs, such as the Office of AIDS and the Office of Obesity and Nutrition.

CHAPTER 5
Preparing Teachers and Other School-Based Personnel to Educate Children With ASD

Findings

- There is a compelling need to increase the number of well-trained special education and regular education teachers, speech and language therapists, behavior therapists, occupational therapists, counselors, and other specialists to meet the educational needs of children with ASD.
- Current practices must be reviewed to ensure that teacher training and preparation are appropriate and applicable to meet the educational needs of children with ASD.
- There is an insufficient number of well-trained paraprofessionals and school aides to assist teachers.
- Teachers report that they need more resources and supports to optimize the education of children with ASD.
- School administrators and principals require additional training and preparation to effectively support teachers who are educating children with ASD.
- Teachers need expanded opportunities for pre-service and in-service training.

Goal

- Ensure there is an adequate number of appropriately trained school personnel to provide educational services to meet the special needs of children with ASD, which will also improve transitions for children with ASD when they change schools and progress through their education.

Policy Recommendations

1. **Establish an alternative credentialing program, at one or more sites, with specialized training on ASD for prospective special education teachers that**

will serve as a template that can be expanded and replicated to accomplish the following:

- **Increase the number of well-trained and qualified teachers; and**
- **Prepare teachers with the specialized competencies they need to educate children with ASD.**

2. **Direct the California Department of Education to establish an Autism Spectrum Disorders Multidisciplinary Educational Training Team Program at multiple sites, including sites in underserved communities, that will serve as a template that can be expanded and replicated to accomplish the following:**

   - **Establish the professional competencies, resources, curricula, and other criteria that should be integrated within each program, including classroom-based practice with oversight and feedback and use of educational best practices for ASD;**
   - **Establish strategies, mandatory trainings, and other services to provide necessary resources and supports for school-based personnel, including general education and special education teachers, preschool teachers, teacher aides, administrators, and other personnel; and**
   - **Promote collaboration in the sharing of information between local education agencies, colleges and universities, diagnostic centers of the California Department of Education, nonpublic schools, nonpublic agencies, and other ASD training providers.**

3. **Establish a model program, at one or more sites, to provide specialized training, including competencies on ASD, and career-ladder opportunities for teacher aides and other paraprofessionals. Appropriate compensation for teacher aides and other paraprofessionals is critical to retain trained staff and encourage their progression in the teaching field.**

4. **Increase funding to local education agencies for professional development days and require the new funds to be used for mandatory ASD-related training of school-based personnel.**

Background

California's public education system is struggling to meet its responsibility to provide a free and appropriate public education to children with ASD, given the significant growth in the number of children diagnosed with these disorders. Local education agencies in California, primarily school districts, have the front-line responsibility to ensure that children with ASD receive an appropriate education. Meeting this responsibility means ensuring that school principals, general education and special education teachers, and other school-based personnel get the training and support they need to understand and respond to the unique needs of children with ASD. This need is not confined to special education programs and staff. Local school district boards and administrators are in the direct leadership position to provide schools with training on ASD and related administrative support. It is essential that school boards and administrators recognize the value of providing such resources. The state must also embrace its key role in helping local education agencies and schools by sharing information about effective educational practices for ASD and providing educators with specialized training and technical assistance.

Assembly Bill 2513: Supporting Schools to Better Serve Children With ASD

Assembly Bill 2513 (Pavley), Chapter 783, Statutes of 2006, recognizes the role of the state in helping public and nonpublic schools to better serve children with ASD. The law requires the state superintendent of public instruction to develop recommendations for (1) the creation of a statewide clearinghouse on research-based educational practices to support children with ASD, (2) informing schools about effective educational practices for ASD and outreach services available to children with ASD and their families, and (3) the need for a technical assistance program to assist schools with teacher training and development of effective ASD programs. The superintendent convened an Autism Advisory Committee for this purpose to submit recommendations to the Legislature by November 1, 2007.

The Commission supports the intent and goals of Assembly Bill 2513 and looks forward to opportunities for collaboration with the superintendent, the Department of Education, and other education partners to advance common goals and recommendations. The Commission's recommendation for the Department of Education to establish the Autism Spectrum Disorders Multidisciplinary Educational Training Team Program is a major step toward meeting the intent of Assembly Bill 2513.

A Responsibility to Provide a Free and Appropriate Public Education

The federal Individuals with Disabilities Education Act and related California education laws place responsibility on the state and local education agencies for providing specialized educational and related services to children ages three to 22 who have disabilities, including autism, so they may benefit from a free and appropriate public education, and in the least restrictive environment. Nearly 40,000 California preschool and school-age children with ASD between the ages of three and 22 now receive special education services from local education agencies.[66] In addition, an unknown number of children with high-functioning ASD are educated through regular education programs.

Federal and state laws do not prescribe specific educational entitlements for certain special education services. Local agencies must evaluate a child's disability and needs for educational programming, develop an individualized education program to meet that child's needs, and provide services according to the child's program. The program is developed by a team, including parents, clinicians, school personnel, teachers, and other experts or advocates.

Children with disabilities may be educated in mainstream classrooms full time or part time, in specialized classrooms within the regular school, or in a specialized public or nonpublic school for children with special needs.[67] A teacher's aide may provide full-day or part-day assistance. Placement in a nonpublic school or program may be financed by a local education agency when it is determined that a public school program cannot offer the appropriate services for a free and appropriate public education.

Educational and Related Services Provided to Children With ASD

According to data provided by the California Department of Education, for the nearly 35,000 children with ASD (ages three to 22) who received special education services during the 2005-06 school year, roughly 86 percent were educated within regular public schools.[68] About 43 percent of children spent more than 80 percent of their time outside regular education settings, and 29 percent spent 20 percent or less of their time outside regular education settings. Nearly 72 percent of children received speech and language therapy. Other services provided most frequently included transportation (34 percent of children), occupational therapy (34 percent), adapted physical education (23 percent), resource specialist/nonintensive specialist programs (18 percent), and behavior intervention (17 percent). Only about 10 percent of children attended a specialized public or nonpublic school for children with

special needs. Less than 2 percent of children had language in their individualized education program that requires a child to receive mental health services.

A Need for Comprehensive Programs and Qualified Educators

Regardless of the setting in which they are educated, all children with ASD are entitled to qualified teachers and other educational service providers who understand their unique cognitive, behavioral, and social skills needs and are able to provide effective educational interventions to meet those needs. Teachers of general education and special education, teacher aides, speech and language therapists, school administrators, school psychologists, and other staff who serve children with ASD must be properly trained with the competencies to deliver effective educational interventions for ASD.

The Commission was told that some local education agencies have developed or are in the process of developing comprehensive educational programs for children with ASD, and that these programs are very costly to operate. These agencies fear that their successful programs will become "magnets," attracting families to move to their areas solely to receive ASD services. The Commission also received testimony from many parents and other observers that some local education agencies have not responded with appropriate, quality programs for students with ASD. Inconsistency in ASD programs across local education agencies can create difficult transitions for children when they change schools and progress through their education.

Fiscal Challenges for Local Education Agencies

Providing a student with ASD with appropriate educational and related services is reported to cost local education agencies significantly more than the cost of educating regular education students and students with other disabilities. According to the 2007 report "Getting Down to Facts: School Finance and Governance in California," the estimated cost of educating the average regular education pupil and special education pupil in California is about $8,000 and $11,600 respectively, based on 2004-05 dollars.[69] On average, spending for pupils with autism is estimated to cost almost $36,000 per pupil, according to the 2006 report "Considering Special Education Adequacy in California."[70] This estimate is confirmed by some local education agencies that indicate it costs at least $30,000 per year to educate a pupil with autism in a public school program and $40,000 per year to send a pupil to a nonpublic school program.

Costs vary depending on a child's level of functioning and the services provided by the local education agency. A local education agency can spend more than $100,000 per year to serve a pupil with severe autism.[71] One school district spent more than $222,000 to educate one student with autism in 2004-05.[72] The 2004 report "Study of the Incidence Adjustment in the Special Education Funding Model" stated that students with autism made up nearly 50 percent of the high-cost special-education school-age population in 2002.[73]

Expanding Educator Training on ASD

Local education agencies that have developed or are in the process of developing comprehensive ASD programs are struggling to train their educators on evidence-based educational practices for ASD. In some cases, these agencies have partnered with nearby public or private universities to expand ASD training for current and/or future educators. Local education agencies may also receive training services from one of the three diagnostic centers operated by the California Department of Education in Los Angeles, Fresno, and Fremont. The centers are intended to help local education agencies meet the educational needs of California's most difficult to serve special education students. The centers provide comprehensive assessments to special education students and staff development and training services to local educational agencies. Services are provided by expert interdisciplinary teams of diagnostic professionals, including educational specialists, speech and language specialists, psychologists, pediatricians, and other specialists. In 2005-06, ASD was the subject of the most staff trainings provided by diagnostic center personnel in response to local and statewide needs.[74]

Presently these training efforts reach an extremely limited number of current educators and individuals preparing to enter the education field. As a whole, across California's public education system there is a significant and serious lack of specialized training on ASD. There is a critical need to expand in-service and pre-service training on ASD and ensure that such training is comprehensive and addresses the behavioral and social skills needs of children with ASD in addition to their cognitive development. Many families told the Commission that teachers and other school staff are especially ill-equipped to address children's behavioral and social skills problems. The need for teachers and other personnel qualified to educate children with ASD will only grow as more of these children enter and progress through the educational system.

Recruitment and Retention of Special Education Teachers

At the same time, local education agencies are facing other systemic challenges that affect their ability to recruit and retain qualified teachers, especially special education teachers. The system is facing a large number of teacher retirements in future years, a very high rate of turnover among special education teachers, and a shortage of prospective special education teacher candidates in the pipeline to replace the current teaching workforce.

It is widely recognized that special education teachers have a high rate of turnover and are more often underprepared than general education teachers, particularly special education teachers for poor and minority students.[75] Lack of time for collaboration with general education staff and inadequate professional development are among the key reasons cited by special education teachers for leaving the field. Research shows that opportunities for professional development and collaboration are critical factors in job satisfaction.[76]

The Promise of Alternative Special Education Credential Programs

One innovative and promising approach to increasing the supply of special education teachers with competencies in ASD is to implement alternative special education credential programs. Alternative credential programs provide a route into teaching for individuals who might not otherwise enter the profession, and for those populations that are now underrepresented in the teaching force. Racial diversity is twice as great among teaching interns in alternative credential programs compared to the current teaching force. There are also many males entering alternative credential programs. Nearly 40 percent of interns in these programs enter teaching after having a prior career.[77]

The retention rate among teachers who complete alternative credential programs—85 percent over five years—is far greater than teachers who attend university-based programs.[78] Alternative credential programs have proven successful in helping to increase the number of qualified special education teachers. Expansion of these programs in California would help the state develop the qualified, competent workforce needed to educate the growing number of pupils with ASD.

Revision of the Special Education Credential Structure

The California Commission on Teacher Credentialing (CTC) is currently engaged in a review of California's special education credential structure. The CTC created a

special education credential workgroup to make recommendations for modifications to the special education credentials. The Special Education Credential Workgroup is recommending a revision to include authorization for serving students with ASD in all special education credential areas. The Commission will take action on this recommendation at its December 5-6, 2007 meeting. If approved, this recommendation would serve as a means to increase the number of special education teachers with expertise in ASD.

CHAPTER 6
Resolving Service Disputes Effectively and Equitably

Findings

- Consumers and their families may disagree with local education agencies and/or regional centers and other systems of care about the necessity for services and the type and quantity of services the consumer and family require, particularly when children transition across systems, service agencies, and programs.
- The current system that addresses conflict resolution between consumers and their families and local education agencies and/or regional centers is variable in its effectiveness across the state.
- Some disputes that are appealed to the state for resolution through mediation and state administrative hearings, or taken to court, can be very costly, frustrating, and time consuming, and create delays in the delivery of services ultimately deemed to be needed. Serious disputes can also divert resources from services.
- The resolutions of some disputes through mediation and state administrative hearings are unsatisfactory to consumers and their families and perceived to be inequitable.
- There is inadequate information about the range of disputes that are resolved at the state and local levels.
- There is inadequate information about the range of possible barriers that may preclude consumers and their families from pursuing an appropriate and effective dispute resolution process.

Goal

- Ensure that consistent and effective standards and practices are used by local education agencies and regional centers to resolve service disputes in a timely, equitable, and cost-effective manner.

Policy Recommendations

1. **Expand the development and broad implementation of effective models for dispute resolution involving special education services, including existing models that successfully integrate local education agencies and families into collaborative decision making. Models would include parent ombudsman programs, training, and other enhanced communication strategies to resolve disputes effectively and empower families to have meaningful participation at the negotiation table with local education agencies. Model programs should include efforts to promote a child's smooth transition to local education agency programs for children at age three.**

2. **Direct the state of California to provide a comprehensive and independent review of the process for resolving disputes at the state and local levels regarding the Early Start, special education, and regional center services for individuals with ASD. The review should determine the nature of the disputes, different resolution processes, outcomes for individuals, families and service agencies, effective models of dispute resolution, factors associated with successful outcomes, and differences across service agencies.**

3. **Direct the Department of Developmental Services and the Department of Education to collect information from regional centers and local education agencies about their legal and other costs for formal dispute resolution and litigation involving persons with ASD.**

Background

Families, local education agencies, and regional centers have struggled to respond to the service needs of children with ASD under extremely challenging circumstances. They need to decide on appropriate educational and other interventions for children with ASD at a time when the field is still trying to understand the efficacy of such interventions.[79] It is widely understood that children with ASD need effective interventions to improve their functioning and outcomes, and treatment should be tailored to address the individual's needs. Research indicates that some interventions have a high degree of efficacy for treating certain symptoms of ASD in some children.[80] However, there are no widely accepted guidelines on exact program components of effective ASD interventions, nor is it clear what constitutes optimal treatment based on an individual's age, symptoms, and level of functioning.

Consequently, parents, service agencies, and experts may come to different conclusions about the needs of a particular child. Furthermore, there is a shortage of qualified and trained providers across the educational and medical disciplines to deliver interventions for ASD, making it difficult for service agencies to hire qualified providers. In addition, it can be very costly to fund complex, intensive interventions for ASD. Nonetheless, service agencies are responsible for providing appropriate interventions regardless of cost and the availability of providers.

The Commission received numerous comments from parents and family advocates that some service agencies do a much better job than others at managing these challenges to serve children with ASD. The Commission was told that there is a lack of consistency in the types of services and level of service provided within and across both the regional center and educational systems. Children can receive vastly different services depending upon which regional center and local education agency area they reside in. The Commission also received testimony that some regional centers help fill gaps in service provision when local education agencies deny services that are their responsibility. There is a common perception that some service agencies are hesitant or resistant to providing comprehensive services for ASD out of fear they will become "magnets," attracting more families to move to their areas solely to receive their services. Finally, the Commission received input that families may request certain types of services or a level of service that goes beyond what experts or research-based practices suggest would be appropriate for a particular child.

Under these circumstances, families and service agencies may have serious disagreements about the service needs of an individual with ASD. Service disputes can be very frustrating for all parties, particularly families after they have struggled to get their child diagnosed. Even more important, long service disputes that last for several months or more may delay a child from receiving necessary services during a critical window of opportunity for early intervention.

Families' Rights to Participation and Fair and Impartial Dispute Resolution

Federal and California education laws create procedural safeguards and rights for pupils and their families to ensure that families have opportunities for meaningful participation in their child's educational programming and access to a fair and impartial process for resolving concerns about educational services. In addition, California's Lanterman Act and related laws establish processes and rights for individuals with developmental disabilities and their families to participate in their

own program planning and access a fair and impartial process for resolving disputes about regional center services.

Within both the education and regional center systems, families and service agencies are encouraged to resolve service disputes informally at the local level whenever possible. In the education system, disputes are addressed at multiple steps, according to the "chain of command" within schools and school administrations. In both the education and regional center systems, families have rights to resolve their concerns through a fair and impartial administrative hearing at the state level before a person who is knowledgeable of the laws governing the applicable programs. Parties may resolve their issues through mediation or alternative dispute resolution rather than take the case to an administrative hearing. Families may also file compliance complaints with the relevant state agencies, either the California Department of Developmental Services or Department of Education, when they believe the local entity has violated a federal or state law.

The California Department of General Services, Office of Administrative Hearings, is the entity currently charged with conducting administrative hearings and mediations for special education and regional center services, including Early Start services. Disputes regarding special education services are handled separately from disputes about regional center services. The Office of Administrative Hearings indicated that it used a coordinated hearing in one case involving disputes about both a regional center's and a school's services. The office provides independent administrative law judges across regional offices to conduct hearings and issue rulings. The office indicates it "will endeavor to provide a generally consistent hearing process among all of the regional offices and administrative law judges. However, each administrative law judge has an individual responsibility to hear and resolve issues that come before him or her. As is true with any adjudicative body, administrative law judges may not always agree on the correct manner in which to interpret the law."[81]

Families' Concerns About Dispute Resolution

The Commission was informed by many families and representatives of state and local agencies that the majority of ASD service disputes are addressed at the local level. Many disputes are resolved to mutual agreement, indicating that some service agencies effectively communicate and negotiate with families. During the past few years, a limited amount of special education funding has been set aside by the state to promote local alternative dispute resolution in special education through Special Education Local Plan Areas. A total of $300,000 has been available on an annual basis

to fund $15,000 grants to 20 local education agencies. With these funds, local agencies are supposed to develop and test procedures, materials, and training to help prevent disputes from happening or becoming more serious. Several enhanced communication models are used, including parent ombudspersons. It is important to understand how some agencies are successful at avoiding and resolving issues and to promote greater use of these practices statewide.

In some cases, families simply drop their concerns because of the overwhelming task of contesting the agency on "an uneven playing field." The Commission received testimony that many families lack the ability and resources to effectively pursue and present their cases through hearings or mediations, while local education agencies have larger budgets to fund legal and other experts. The ability of parents to be strong advocates can depend on their educational backgrounds, understanding of their rights, financial resources, and communication abilities. Families may be unable to advocate for services due to language barriers and cultural factors. They may be unable to take time off from work or obtain child care to participate in meetings and hearings. They may be incapable of financing the necessary independent expert evaluations and legal representation to successfully challenge denials of services. One family reported spending as much as $30,000 to take its case to a hearing.

Some local education agencies have spent much more on their legal costs. For example, the California Association of Suburban School Districts reported that in 2003-04 the Las Virgenes Unified School District spent almost $900,000 in legal fees, mostly for a single ASD-related case that went to litigation. In 2004-05 the Long Beach Unified School District spent over $205,000 in legal fees for 13 cases, nine of which involved students with ASD. The Ojai Unified School District in Ventura County, a small district with 40 students with ASD, spent $400,000 in 2004-05 on ASD-related legal costs.[82]

Many families told the Commission that, on the whole, regional centers are more effective than local education agencies in coming to common terms with families about a child's service needs. While local education agencies are responsible for educational and related services for children with ASD between ages three and 22, regional centers typically have a larger role in service provision for children younger than age three and persons who age out of the school system.

Some families expressed their beliefs that administrative law judges from the Office of Administrative Hearings are deciding the vast majority of special education disputes in favor of local education agencies and that this demonstrates that the

process is unfair and inequitable to many individuals with ASD and their families. Other families voiced concerns to the Commission about inconsistency in the hearings process due to differences in how administrative law judges interpret the law and the evidence-base for ASD interventions. However, some local education agencies indicate that the administrative hearings process is consistent in using legal procedures and interpreting current law.

Disputes About a Free and Appropriate Public Education

A central issue in many disputes between families and local education agencies is the question of what services a child is entitled to as part of a free and appropriate public education (FAPE). What constitutes a FAPE for students with disabilities is often debated. In 1982 the U.S. Supreme Court ruled in *Board of Education v. Rowley* that the standard necessary to provide a FAPE to pupils with special needs as that necessary to provide "some educational benefit," not maximum educational benefit.[83] Based on this standard, local education agencies may have different views of their responsibilities to fund high-cost interventions for pupils with ASD. Some families and advocates told the Commission the state should adopt a higher standard than the *Rowley* standard for educating students with disabilities. The implications of the federal No Child Left Behind Act and the 2004 Individuals With Disabilities Act, which both emphasize research-based educational practices, must also be considered when assessing FAPE.

According to the California Department of Education, disputes involving ASD frequently relate to the child's educational placement, the child's service needs, privately provided services, behavior modification therapies, and accuracy of the child's educational assessment.[84]

A Need for a Comprehensive Review of ASD Service Disputes

Due to a lack of information, it is not possible to thoroughly understand and evaluate the range of disputes about local education agency and regional center services for ASD, including disputes resolved at the state and local levels and issues that families are unable to pursue. Given the concerns that families have reported about service disputes, the state should contract for a comprehensive and independent review of ASD service disputes. A review is needed to understand the nature of disputes and how they are addressed, as well as to identify any major inconsistencies in service provision and dispute resolution across regional centers and local education agencies. Such a review would also help identify effective models of dispute resolution that could be expanded to other areas. It is essential

that disagreements between families and service agencies be resolved in a timely, fair, equitable, and cost-effective manner for all parties.

CHAPTER 7
Designing New Employment and Housing Strategies for Individuals With ASD

Findings

- Within the next few years, a significant number of young people with ASD will enter adulthood and transition into the community.
- There are very few programs designed to meet the needs of these individuals in the areas of specialized employment, education, and housing. California has three to five years to prepare for this unprecedented demand.
- There is a lack of effective models that address the career technical educational (vocational) needs of individuals with ASD who require intensive supports and assistance.
- Although new initiatives have begun to expand self-directed service delivery models, there are major gaps within the private and public employment sectors related to the broad scope of skills, interests, and abilities of the ASD population.
- There are few, if any, specialized services designed to meet the needs of higher functioning adolescents and adults with ASD to enable them to develop vocational skills and assist them in finding productive career pathways. Currently, there is only one program at the community college level (Taft Community College) that provides these specialized services, and it has a five-year waiting list. In addition, the University of California, Santa Barbara, has a new specialized program for high-functioning pupils with ASD so they may obtain four-year university degrees. This project is funded by the Eli and Edythe L. Broad Foundation through the Koegel Autism Center. Many more such programs are needed within California's colleges and universities.

Goal

- Develop and implement models that effectively address the educational, housing, transportation, social-recreational, and employment needs of adolescents and adults with ASD so they have equal opportunities to achieve a high quality of life.

Policy Recommendations

1. **Direct the California Community Colleges, in collaboration with other appropriate public and nonpublic partners, to expand community college-based programs designed for career training of people with ASD across levels of functioning.**

2. **Direct the California State University and the University of California systems to promote multiple educational pathways for persons with ASD.**

3. **Direct the California Department of Education, in collaboration with other appropriate public and nonpublic partners, to establish a demonstration project at multiple sites that will serve as a career technical educational pathway, starting in middle school, for students with ASD who require intensive supports and assistance.**

4. **Endorse the efforts of the State Council on Developmental Disabilities in implementing the recommendations of Senate Bill 1270 (Chesbro), Chapter 397, Statutes of 2006, by promoting innovative career training programs for persons with ASD in California by 2009.**

5. **Enact a state housing financing program designed to add financial support and assistance to local housing initiatives that bring together families, regional centers, and other community organizations for the development of specialized housing for the ASD population. This program would explore ways that tax credits, other fiscal strategies, and nonfiscal approaches could be used to promote housing (including reinvestment of revenues from the sale of surplus property, changes in local zoning laws, and other approaches).**

6. **Create a model for housing and supporting persons with ASD that treats individuals with respect and dignity, includes supported living services, promotes career and daily living skills, and provides a range of opportunities for employment and leisure activities.**

Background

California is experiencing a massive increase in children and adolescents with ASD served by regional centers and schools. This tsunami wave of young people with

ASD needs to be recognized, and policies and programs need to be reformulated to address the major increases in the population as it ages into adulthood over the next three to five years.

Presently, the state's systems for adults with disabilities have not been designed to serve persons with ASD. Rather than fitting the "square peg into the round hole," the state needs to review both the design and adequacy of its programs for employment, adult and higher education, supportive housing, self-directed, and long-term support services. Every major initiative that is intended to address unmet needs in California (for example, housing bond funds, Proposition 63 mental health funding, and other sources) needs to be reviewed with an eye toward assuring that persons with ASD have full access and integration into various community improvements.

Every person with ASD transitioning into adulthood needs a life plan that addresses their educational, social, residential, and employment supports and is developed with the person, family, friends, and community supporters. Not all persons with ASD are eligible for services in the state developmental services system. The state could provide families with effective tools for planning, utilizing the services of other state programs when appropriate (for example, community colleges and universities, employment and career training, and other programs). Those not eligible for regional center or special education services will nonetheless turn to other existing service systems. These systems also need a conscious effort of adaptation to better serve this population.

Further, many state service programs for persons with disabilities respond to crises when maintenance of functional level is often the critical goal. Rather than offering access to services to prevent deterioration, our public programs often offer nothing until something goes wrong. Services should not be predicated on a punitive model—that is, offered only in response to a crisis. State and local partnerships in policies and programs, public-private partnerships and programs, and personalized planning based on the person's strengths (gift-based, not disability-based assessments and planning) all need to be done in the context of interagency collaboration and cooperation involving all the relevant agencies of government.

CHAPTER 8
Increasing Awareness and Knowledge of ASD Among Law Enforcement Officers and Other First Responders

Findings

- While police and fire departments have attempted to stay abreast of specialized trainings needed to address certain populations of a community, there are already reports of devastating incidents arising from a lack of understanding and training on how to appropriately respond to events involving persons with ASD.
- The full range of first responders lack fundamental skills in understanding and responding to this population.
- As the ASD population grows into adulthood, it has a right to know what to do when victimized.
- Courts lack an awareness of persons with ASD who may interact with the judicial system in various ways.

Goal

- Assure full integration of persons with ASD into community life in California through prevention efforts that prepare and educate first responders, the judicial system, and the persons themselves on these aspects of functioning within a community.

Policy Recommendations

1. **Direct the Peace Officer Standards and Training Commission to develop an ASD training module (for example, DVD-based technology) and make it widely available to peace officers and first responders.**

2. **Direct the Department of Developmental Services and the Judicial Council to initiate training for persons with ASD, as well as for allied public agencies, on how to access and participate in the judicial system.**

Background

If the state does nothing, the aging ASD population could tragically parallel many of the negative impacts the seriously mentally ill have suffered after deinstitutionalization in California. Persons with ASD can be misunderstood easily by first responders. The state has a choice to serve this group by a public response one way or another—humane policies and informed programs aimed at prevention of criminal justice involvement or social isolation and rejection followed by poverty, homelessness, and a dehumanizing criminal justice system.

Persons with ASD may be very concerned about their ability to accurately communicate with those around them. However, some of the behavioral characteristics of persons with ASD can be read as hostile and uncaring. Many persons with ASD, especially those who require substantial care and supervision, can become victims of unscrupulous people who prey on the vulnerable; people with ASD are particularly disadvantaged because many are unable to successfully access help when they need it from the police, courts, and others.

California has addressed this problem with other populations and has found cost-effective ways of educating first responders as well as persons with disabilities who need to develop skills to function effectively in a community. As the ASD population grows into adulthood, it will need similar attention and accommodation.

The Peace Officer Standards and Training Commission previously developed two training videos regarding persons with disabilities. The first video, produced in 1995, deals with many disabilities, including autism, but the content is not very specific about the needs and behaviors of persons with autism. The second video, released in 2005, focuses on interviewing persons with disabilities, but does not discuss autism. Neither video provides comprehensive information to adequately train law enforcement officers about autism. For instance, training is needed to make officers aware that persons with autism may not show physical signs of having a disability and they may appear nonresponsive to questioning or directions. Officers need to demonstrate patience and a special understanding when interacting with the autism population.

CHAPTER 9
Conclusions and Next Steps

The Commission's work shows that the state of California needs to conduct comprehensive planning and policy development across a broad range of constituents to effectively respond to the ASD public health crisis. There are many gaps in programs, services, and funding for Californians with ASD and their families. These gaps cross multiple systems of care and affect Californians with ASD across their life span, from early childhood through adulthood. California has no time to waste in developing a more comprehensive response to these gaps. The crisis is here and is multifaceted, requiring collaborative solutions that span multiple disciplines, levels of government, and public and private entities. As a result, the State Legislature and Governor Schwarzenegger may wish to consider designating ASD as a public health emergency in California.

The Commission's recommendations provide an initial roadmap for the state to begin addressing the most urgent needs for Californians with ASD, their families, and service systems. The Commission urges the State Legislature and Governor Schwarzenegger to adopt these recommendations by enacting legislation the Commission will offer in the next legislative year. The ensuing legislative discussion must include a comprehensive fiscal review and analysis of current state spending on programs and services for ASD and the impact of the Commission's recommendations.

The Commission also urges state policymakers to make ASD an important public policy priority during the next three to five years. As part of an ASD public policy agenda, there should be greater coordination in planning and policy development across the state agencies that have key roles and responsibilities for helping Californians with ASD and their families. The state departments of Developmental Services, Education, Managed Health Care, and Public Health should collaborate and work with other state, local, and private partners and families to improve ASD programs and services and include a greater focus on ASD across systems that have not traditionally focused on this population. The Commission considered making a recommendation to establish an interagency working group on ASD to bring together the relevant parties for greater collaboration; while the Commission believes stronger leadership on ASD and interagency collaboration are critically needed, the Commission is not clear about which state agency or agencies should be charged with the accountability to lead the charge on

ASD and convene this working group. Nonetheless, the Commission hopes the Administration will take steps and devote resources to convene an ASD working group and achieve comprehensive planning and policy development on ASD.

The Commission also encourages county governments and other partners to conduct collaborative planning and policy development on ASD at the local level, since there is great potential to include a focus on ASD in existing early identification, screening, and referral programs. For example, some counties have developed pediatric developmental screening and assessment programs to address the problem of drug-exposed infants. These programs could be broadened to include all children from birth to age five in need of comprehensive developmental assessments and support.

It is clear that much work remains to be done beyond these first steps. Given its allotted time frame, it was not feasible for the Commission to develop recommendations to address all the issues identified by families and other ASD stakeholders. The Commission had to prioritize issues for immediate action, leaving other issues for further work. The following "rules of the road" were used to guide the Commission and its three task forces in prioritizing issues:

- Parents and individuals working in the field believe there is an immediate critical gap or problem to address.
- The state has a clear role and responsibility to address the issue.
- The potential solution is clearly identified and feasible to implement.
- The solution to the problem is cost effective, meaning it is the right thing to do at the right time.
- The solution is consistent with the state's values, role, and responsibilities.
- The outcomes of the solutions recommended can be measured and quantified.
- The solution has the potential for systemic change that would benefit a larger population of children with developmental needs in addition to those with ASD.

Several important issues identified through the Commission's work warrant further analysis to identify appropriate solutions. First, there is an insufficient number of developmental pediatricians, speech and language therapists, behavioral therapists, occupational and physical therapists, psychiatrists, psychologists, primary care physicians, neurologists, and other health care providers to provide services to individuals with ASD, both children and adults across their life span. California's colleges and universities have a central role in the preparation of persons entering these fields and often in training for professionals currently in the field. The Commission proposes to work with California's higher educational systems to

explore options and opportunities to increase specialized education and training on ASD for such professionals.

Second, low-income Californians who receive health and mental health care services through the Medi-Cal Program experience serious problems locating primary care and other health care providers with expertise in ASD. Access to health care providers is an endemic problem for persons served through the Medi-Cal Program for reasons largely related to low provider-reimbursement levels. Access to providers who specialize in ASD is part of a broader policy discussion about barriers to services in the Medi-Cal Program.

Third, a diagnosis of autism does not entitle children and youth who are full-scope Medi-Cal eligible and under age 21 to receive specialty mental health services through county mental health plans under the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit. Under the Lanterman Developmental Disabilities Services Act, children with a diagnosis of autism are entitled to necessary services provided through their designated regional center. Although regional centers must first seek any medically necessary services available under Medi-Cal, EPSDT eligible children and youth must still meet the medical necessity criteria for EPSDT specialty mental health services.[85] EPSDT specialty mental health services are outpatient services and include a full array of rehabilitative mental health services as outlined in Title 9, California Code of Regulations.[86] Autistic disorder is not included among the qualifying diagnoses for determining medical necessity criteria for EPSDT specialty mental health services, even though other pervasive developmental disorders are qualifying diagnoses. Although autistic disorder is excluded from the qualifying diagnoses, this does not prevent children and youth who are seriously emotionally disturbed and have a dual diagnosis of autism from receiving medically necessary EPSDT specialty mental health services. It is not clear how the exclusion of autistic disorder as a qualifying diagnosis could affect children's access to mental health services, given the responsibilities of regional centers and local education agencies to provide services to children with autism. Further analysis of this issue is necessary.

Fourth, there is a need for long-term monitoring of the efficacy, or alternatively any specific risks, of the interventions and treatments provided to individuals with ASD. Long-term quality assurance of interventions and treatments is critical to ensure that individuals receive the most appropriate services without fear of unforeseen negative impacts. The Commission believes that the State Department of Public Health would have an important role in developing and implementing such efforts.

Fifth, the needs of older adults with ASD must be addressed in a comprehensive way as the ASD population, their parents, and other caregivers for this population age. Many persons with ASD continue into adulthood to live with their parents. These families will need assistance in long-term planning around financial and legal issues so that the individual's needs are met when their parents are no longer available to assist them.

Finally, it is critical to address the far-reaching problem of inadequate compensation for service providers across systems of care. Low pay scales and reimbursement rates must be increased and other incentives should be created to attract and maintain more professionals and paraprofessionals in the health care, education, and developmental services systems to serve persons with ASD and other special needs.

During the year ahead, the Commission looks forward to working with state policymakers on the recommendations and other issues identified in this report.

Appendix A
Senate Concurrent Resolution 51

Senate Concurrent Resolution No. 51
RESOLUTION CHAPTER 124
Senate Concurrent Resolution No. 51—Relative to autism spectrum disorders.
[Filed with Secretary of State September 14, 2005.]

LEGISLATIVE COUNSEL'S DIGEST

SCR 51, Perata. Legislative Blue Ribbon Commission on Autism.

This measure would establish, until November 30, 2007, the Legislative Blue Ribbon Commission on Autism. The measure would require the commission to report related findings and recommendations to the Governor and to the Legislature no later than September 30, 2007.

WHEREAS, Autism and autism spectrum disorders, or ASD, are neurodevelopmental disorders of unknown etiology that may cause significant impairments in language, communications, social interactions, abnormalities in behaviors, and other physical manifestations; and

WHEREAS, Autism spectrum disorders are abnormalities of brain development and function that are typically diagnosed during the first three years of life, are four times more likely to occur in males than females, and impact all segments of California's population regardless of race, ethnicity, socioeconomic status, or other factors; and

WHEREAS, Autism is the fastest growing serious developmental disability in California. Presently, one out of every 166 children is afflicted with some form of autism spectrum disorder; and

WHEREAS, The State Department of Developmental Services (DDS) has established that California's autism caseload increased by 634 percent from 1987 to the end of 2002. In the four years between 1998 and 2002, the total number of persons with autism served by the regional centers had more than doubled and had reached 20,377. Presently, there is a net increase of approximately 3,000 persons with autism added to the DDS service delivery system annually; and

WHEREAS, The percentage increase in the number of individuals with autism who received services from DDS during the first quarter of 2005 more than tripled the

percentage increase in the number of individuals for the three other primary types of developmental disability combined; and

WHEREAS, At present, approximately 77 percent of all individuals with autism served by DDS are under the age of 18 years; and

WHEREAS, The State Department of Education reported that in the 1992-93 school year, there were 1,982 students enrolled with autism in grades K-12, while in 2004, the number of students with autism had increased to 21,948; and

WHEREAS, The number of students with autism enrolled in grades K-12 has increased over 1,000 percent during the past 22 years; and

WHEREAS, The State Department of Education reports that nearly every part of California has seen a doubling of the incidence of students with autism in grades K-12 over the past four years alone; and

WHEREAS, The number of students with autism in proportion to the total student enrollment, and also in proportion to students enrolled in special education, has more than quadrupled during the last nine years; and

WHEREAS, The State Department of Education reports that not only are there drastically more K-12 students afflicted with autism, but the students with autism comprise a significantly greater proportion of the special education population; and

WHEREAS, The economic impact of autism in the United States is more than $90 billion annually and is expected to more than double in the next decade; now, therefore, be it

Resolved by the Senate of the State of California, the Assembly thereof concurring, That the Legislative Blue Ribbon Commission on Autism is hereby established to study and investigate issues, including, but not limited to, the early identification and intervention of autism spectrum disorders (ASD). Further, the commission shall identify gaps in programs, services, and funding related to the early identification of ASD and provide recommendations to close the identified gaps; and be it further

Resolved, That the commission shall identify gaps in programs and services related to the education and treatment of children, adolescents, transitional youth, and adults with autism spectrum disorders. Further, the commission shall provide recommendations for the planning of a comprehensive and integrated continuum of programs, services, and funding that will be required to address the "aging out" of children who comprise the current autism epidemic; and be it further

Resolved, That the commission shall consist of 16 members, who shall include eight members appointed by the Senate Committee on Rules and eight members appointed by the Speaker of the Assembly; and be it further

Resolved, That the commission shall be under the direction of a chair, selected from among its members and appointed by the Senate Committee on Rules, and a vice chair, selected from among its members and appointed by the Speaker of the Assembly; and be it further

Resolved, That the commission shall submit one or more reports to the Legislature and to the Governor, including its findings and recommendations by no later than September 30, 2007; and be it further

Resolved, That the commission is authorized to act until November 30, 2007; and be it further

Resolved, That the commission shall seek funding, technical assistance, and other resources from foundations and other organizations as long as that support would not pose any conflict of interest and would be deemed as consistent with the goals and objectives of the commission; and be it further

Resolved, That the work of the commission may be supported by legislative staff and services as determined by the respective rules committees; and be it further

Resolved, That the commission and its members shall have and exercise all the rights, duties, and powers conferred upon commissions and their members by the Joint Rules of the Senate and the Assembly, as they are adopted and amended from time to time, and the pertinent provisions of the Joint Rules shall be applicable to this commission and its members.

Appendix B
Senate Concurrent Resolution 55

Senate Concurrent Resolution No. 55
RESOLUTION CHAPTER 127
Senate Concurrent Resolution No. 55—Relative to autism spectrum disorders.
[Filed with Secretary of State September 18, 2007.]

LEGISLATIVE COUNSEL'S DIGEST

SCR 55, Perata. Legislative Blue Ribbon Commission on Autism.

This measure would extend the termination date of the authorization to act of the Legislative Blue Ribbon Commission on Autism from November 30, 2007, to November 30, 2008.

WHEREAS, Autism and autism spectrum disorders are neurodevelopmental disorders of unknown etiology that may cause significant impairments in language, communications, social interactions, abnormalities in behaviors, and other physical manifestations; and

WHEREAS, Autism is the fastest growing serious developmental disability in California. Presently, one out of every 166 children is afflicted with some form of autism spectrum disorder; and

WHEREAS, Pursuant to Resolution Chapter 124 of the Statutes of 2006, the Legislature established the Legislative Blue Ribbon Commission on Autism to do all the following:

(a) Study and investigate autism issues, including, but not limited to, the early identification of and intervention in autism spectrum disorders and to identify gaps in programs, services, and funding related to the early identification of autism spectrum disorders, and provide recommendations to close the identified gaps.

(b) Identify gaps in programs and services related to the education and treatment of children, adolescents, transitional youth, and adults with autism spectrum disorders.

(c) Provide recommendations for the planning of a comprehensive and integrated continuum of programs, services, and funding that will be required to address the "aging out" of children who comprise the current autism epidemic; and

WHEREAS, The commission is required to submit one or more reports, including its findings and recommendations, to the Legislature and the Governor by September 30, 2007; and

WHEREAS, The commission is currently authorized to act only until November 30, 2007; and

WHEREAS, By extending the authorization of the commission to act through November 30, 2008, the commission would have sufficient time to monitor the degree to which its recommendations are being implemented; now, therefore, be it

Resolved by the Senate of the State of California, the Assembly thereof concurring, That the commission is authorized to act until November 30, 2008.

Appendix C
Commission Member Biographies

Senator Darrell Steinberg, Commission Chair
Member, California State Senate; Chair, Senate Natural Resources and Water Committee; Chair, Mental Health Services Oversight and Accountability Commission; Author, California State Proposition 63 (2004), Mental Health Initiative

Barbara Firestone, Ph.D., Commission Vice Chair
President, CEO, and Founder, The Help Group, a group of schools specializing in students with autism and learning disorders

Cindy Asner
Parent and activist for better diagnosis and treatment of mental health issues, especially autism

Magdalena Beltran-del Olmo
Vice President of Communications, California Wellness Foundation

Stephen Beneto
Parent; Owner, Beneto, Inc; Board Member, M.I.N.D Institute, University of California, Davis

Maureen O'Leary Burness
Assistant Superintendent of Student Support Services, Folsom Cordova Unified School District, Sacramento, California

Rudy Castruita, Ed.D.
Educational consultant; San Diego County Superintendent of Schools (retired); Irving & Virginia Melbo Chair, Rosier School of Education, University of Southern California

David Feinberg, M.D.
Medical Director, Resnick Neuropsychiaric Hospital, University of California, Los Angeles

Ronald Huff, Ph.D.
Director of Clinical and Intake Services, Alta California Regional Center; Member, Oversight Committee, Department of Developmental Services Autistic Spectrum Disorders: Guidelines for Effective Intervention Project

David Kears
Director, Alameda County Health Care Services Agency, California

Lynn Koegel, Ph.D.
Clinical Director, Autism Services, Koegel Autism Center, University of California, Santa Barbara

Areva Martin, Esq.
Parent; Managing Partner, Martin-Martin, LLP, Los Angeles, California; Co-founder and President, Special Needs Network, Inc.

Rick Rollens
Parent; President, Rollins Consulting; Board Member, M.I.N.D. Institute, University of California, Davis; former Secretary of the California State Senate

Kenneth Simril
President, Fleischmann's Vinegar Company, Los Angeles, California

Eleni Tsakopoulos-Kounalakis
President, AKT Development Company, Sacramento, California

Albert Wang, M.D.
Parent; Partner, Palo Alto Medical Clinic; Founder, Friends of Children with Special Needs

Appendix D
Task Force on Early Identification and Intervention

Barbara Firestone, Ph.D., Chair
Eleni Tsakopoulos-Kounalakis, Vice Chair
Mila Amerine-Dickens
Anshu Batra, M.D.
Elizabeth Bell
Pilar Bernal, M.D.
Andrew Cavagnaro
Teddi Cole
Joan Crear
Lisa Croen, Ph.D.
Joe Donnelly, M.D.
Erin Dubey
Margaret Dunkle
Tammy Forrest, Ph.D.
William Frea, Ph.D.
Barbara Garcia
Tom Gilevich
Greg Girvan
Fran Goldfarb
Cathy Gott
Pat Grayson-DeJong
Karyn Hebbaz
Ronald Huff, Ph.D.
Rick Ingraham
Stephanie Koh
Marc Lerner, M.D.
Debra Merchant
Molly O'Brien
Lark Park
Karen Robinson-Stark
Sally J. Rogers, Ph.D.
Jahn Rokicki
Donna Ross Jones
Andrew Shahan
Donna Spiker, Ph.D.
Laurie Stephens, Ph.D.
Nancy Strohl
Laurie Vismara, Ph.D.
Laura Wasco
Michele Waterman
Gloria Wong
Michael Zito

Appendix E
Task Force on Education and Professional Development

Rudy Castruita, Ed.D., Chair
Areva Martin, Esq., Vice Chair
Ace Atkinson
Cindy Asner
Maureen O'Leary Burness
Faye Carter
Mike Clark
Pamela Colvin-Lee
Ann England
Bob Farran
Nancy Fellmeth
Terilyn Finders
Adele Forbes
Dave Gordon
Maureen Graves, Esq.
Kristin Grodeon
Georgianne Knight
Lynne Koegel, Ph.D.
Janelle Farris Lewis
Dale Mentink, Esq.
Debra Moss
Laurie Stephens
Patricia Schetter
Rebecca Steinberger
Vicki Thomas
Chris Whalen, Ph.D.

Appendix F
Task Force on Transitional Services and Supports

David Kears, Chair
Rick Rollens, Vice Chair
Anita Allardice
Michael Bernick
John Clay
Mark Erlichman
Dick Farmer
Barbara Garcia
Nancy Gardner
Jayne Goldman
Raymond Hampson
Jackie Johnson
Connie Lapin
Bethany Mickahail, Ph.D.
Maggie Roberts
Jeff Ross
Barry Schulman
Chantal Sicile-Kira
Ann Laferty Snowhook
Richard Rosenberg
Marianne Topedtman
John Weber
Caroline Sandberg-Wilson

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