



THE CALIFORNIA SENATE SELECT COMMITTEE ON AUTISM & RELATED DISORDERS

*Partnering with Families and Communities
to Plan for a Brighter Future*



www.senateautismcommittee.gov

SENATE COMMITTEE ON RULES

RESOLUTION NO. 4

Relative to the Senate Select Committee on
Autism and Related Disorders (ASD)

Resolved by the Senate Committee on Rules, that pursuant to Senate Rule 12.5, a Subcommittee of the General Research Committee is hereby created to be known as the **Senate Select Committee on Autism and Related Disorders (ASD)**; and be it further

Resolved, that the Subcommittee shall be composed of **10** members to be appointed by the Senate Committee on Rules; and be it further

Resolved, that the Subcommittee is authorized and directed to provide a legislative forum for research, analysis, deliberations, and outreach in order to promote policies and legislation to better assist individuals with ASD and their families.

Further, the Subcommittee is authorized and directed to advance the work of the California Legislative Blue Ribbon Commission on Autism; to address the issues that were identified within the California Autism legislative Package of 2007-2008; and to deal with the fiscal challenges that confront the State in providing the necessary and crucial services for individuals with ASD; and be it further

Resolved, that the Subcommittee shall submit its report to the Senate, including recommendations for appropriate legislation, no later than November 30, 2010, on which date it shall cease to exist; and be it further

Resolved, that the Senate Rules Committee may allocate from time to time to the Subcommittee from the Senate Operating Fund such sums as are necessary, and may employ and assign such personnel as the Senate Committee on Rules deems necessary for the Subcommittee to complete the investigation or study assigned to it by this Resolution; and be it further

Resolved, that for the purposes of carrying out and implementing its assignments as hereinabove set forth said Subcommittee and its members shall have and is empowered to exercise all of the rights and powers conferred upon investigating committees by the provisions of the Standing Rules of the Senate as adopted and amended from time to time, which provisions

are, by reference, incorporated herein, including the right to hold hearings, to summon and subpoena witnesses (must have prior approval of the Senate Rules Committee), require the production of papers, books, accounts, reports, documents and records of every kind and description, and to take all necessary means to compel the attendance of witnesses and procure testimony; and be it further

Resolved, that the Subcommittee, each of its members, and every representative of the Subcommittee thereunto authorized by it or its Chair, is authorized and empowered to administer oaths (must have prior approval of the Senate Rules Committee); and every department, commission, board, agency, officer and employee of the State Government, including the Legislative Counsel, and of any political subdivision, county, city, or public district of or in the State shall furnish the Subcommittee, upon request, any and all assistance and information, records and documents as it deems proper for the accomplishment of the purposes for which it is created.

Adopted: March 4, 2009

California State Senate

SENATOR
DARRELL STEINBERG
PRESIDENT PRO TEMPORE



The Senate Select Committee on Autism & Related Disorders (Senate ASD Committee)

OVERVIEW & BACKGROUND INFORMATION

Goals & Objectives of the Senate ASD Committee

1. To provide research, analysis, deliberations, and outreach in order to promote policies and legislation to better assist individuals with autism spectrum disorders (ASD) and their families
2. To focus on the following issues related to ASD:
 - Early identification & treatment;
 - Health insurance coverage;
 - Employment;
 - Housing
3. To advance the work of the California Legislative Blue Ribbon Commission on Autism
4. To address the issues that were identified within the California Autism Legislative Package of 2007-2008
5. To deal with the fiscal challenges that confront the State in providing the necessary & crucial services for individuals with ASD

Members of the ASD Committee

- Senate President Darrell Steinberg (Democrat – Sacramento, 6th District) – Chair
- Senate Republican Leader Dennis Hollingsworth (Republican – Murrieta, 36th District)
- Sen. Elaine Alquist (Democrat – Santa Clara, 13th District), chair of the Senate Health Committee
- Sen. Roy Ashburn (Republican – Bakersfield, 18th District)
- Sen. Lou Correa (Democrat – Santa Ana, 34th District)
- Sen. Mark DeSaulnier (Democrat – Contra Costa, 7th District)
- Sen. Dean Florez (Democrat – Shafter, 16th District)
- Sen. Mark Leno (Democrat – San Francisco, 3rd District)
- Sen. Carol Liu (Democrat – Pasadena, 21st District), chair of the Senate Human Services Committee

- Sen. Alex Padilla (Democrat – Pacoima, 20th District)
- Sen. Fran Pavley (Democrat – Agoura Hills, 23rd District)
- Sen. Curren D. Price, Jr. (Democrat – Los Angeles, 26th District)
- Sen. Lois Wolk (Democrat – Davis, 5th District)

Strategic Approaches of the ASD Committee

To establish a **network** of consumers, families, advocates, families, organizations, and other stakeholders that will work closely with the ASD Committee at the local and regional level in close collaboration with District Offices

- To provide an **exchange of information** (i.e. what's working; gaps and barriers; potential improvements; cost-effective strategies)
- To **promote events** that improve collaboration between ASD and other disabilities and special needs
- To submit **recommendations** and provide **assistance** to the ASD Committee

Implementation Strategies of the ASD Committee:

1. The Senate Select Committee will establish **Regional Task Forces (RTF)** throughout the State that will work closely and collaboratively with the Members' district offices (DOs.) RTFs may also explore the possibility of working with other Members (and their DOs) that are currently not affiliated with the Senate ASD Committee.
2. The RTF will be appointed by the DO. Initial leadership teams shall be established and additional members would be included from the community. The RTF would be inclusive and diverse. The RTF shall also partner and work with organizations affiliated with other disabilities and special needs.
3. The specific **goals and activities** of the RTF shall include the following:
 - Establish an advocacy network (individuals, organizations, non-profits etc)
 - Establish and promote innovative approaches to improved communication; information sharing; and new partnerships.
 - Engage and involve local elected officials and policy makers
 - Provide information, strategic approaches, and best practices on effective models in the four topic areas
 - Identify gaps and barriers in existing services and delivery systems
 - Identify innovative funding streams &/or cost savings
 - Conduct Town Hall meetings and other "grass roots" community outreach activities.
 - Promote media coverage

Overarching Concepts & Principles of the ASD Committee

1. To establish an innovative and effective process by which the “voices of consumers, advocates, and family members can be heard.”
2. To establish an infrastructure that promotes useful and productive, inclusive, collaboration and communication and seeks to “find common solutions and approaches” between individuals with ASD and individuals with other disabilities and special needs
3. Focus on consumer-based concepts, which are dedicated to issues of equity and diversity, and also ensure that consumers, parents, & families as well as individuals working in the field must also be involved
4. The ASD Committee’s activities would be linked to the following:
 - The state should have a clear role and responsibility to address these issues
 - The solutions should be clearly identified, reasonable, measurable, and feasible to implement during the current fiscal crises.
 - The solutions should have the potential to effect broad “systems change”

Next Steps for the ASD Committee:

1. Appoint RTF members
2. Organizational meeting of Regional Task Force (RTF)
3. Coordinate activities of RTF with Senators’ District Office
4. Establish workgroups related to the four focus areas (Early Identification/Intervention; Health Insurance; Employment; Housing) Obtain input from ASD Committee District Offices
5. Establish website for ASD Committee and RTFs
6. Create ASD Committee e-letter and additional background information
7. Prepare materials for Senators’ websites
8. Develop strategic plan

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The Senate Select Committee on Autism & Related Disorders (Senate ASD Committee)

Background information on Autism Spectrum Disorders (ASD)

Autism spectrum disorders are complex brain-based (neurological) conditions of development that have an onset in early childhood. ASD includes full spectrum autism and the related disorders: Asperger's syndrome and Pervasive Developmental Disorder, Not Otherwise Specified. 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.

The ASD epidemic is a public health crisis that continues to have a major impact on our state and our nation. Once considered rare, ASD is the fastest growing serious developmental disability and is more prevalent than juvenile diabetes, childhood cancer and pediatric AIDS combined. Nationally, the diagnosis of autism has increased tenfold in the last decade. Presently, about 1 in 150 children are affected by this disorder. Eleven new cases of ASD are being diagnosed every day in California and two-thirds of all new cases that are presently entering the regional center system now involve ASD. Although Regional Centers presently serve about 75-80% of individuals who are diagnosed with full spectrum autism, it is estimated that these consumers reflect only about 20% of all Californians who have some form of this disorder.

The number of regional center consumers in California with ASD continues to skyrocket. In 1993 the regional center clients numbered 4,700; presently there are almost 40,000 consumers diagnosed with ASD. Since 84% of all regional center consumers with ASD are under 22 years of age, the state faces a virtual "tsunami" of young adults who will be transitioning into community-based settings during the next decade. The impact and significance of this "aging out" population is further underscored by the following statistics:

- More individuals with developmental disabilities are living in the home of a parent or guardian (73% in 2006 as compared to 65% in 1996)
- The cost for housing and services for individuals with ASD are expensive; individuals with ASD are more than twice as likely to be in the most expensive 5% of consumers. Service costs are typically double the cost of serving consumers without ASD.
- Regional center costs for ASD increase dramatically with the age of the consumer and average about \$9,800 annually for children but rise to over \$36,600 annually for adults.
- The unemployment rate for regional center consumers who are adults is over 85%; for autism it exceeds 90%. The average salary for those adults who are employed averages \$4,824 annually.
- California ranks 34th in the employment rate of adults with disabilities & special needs

- Regional center costs for transportation average of \$181 Million annually and involve 7.6% of the total budget. These costs will increase significantly as more children with ASD are “aging out” and transitioning to independent living situations in a community setting.

The California Legislative Blue Ribbon Commission on Autism

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. To fulfill its charge, the Commission (Sen. Steinberg, Chair; Dr. Firestone, Vice-Chair) 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 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 findings and recommendations were submitted in its report to the Governor and to the Legislature (September, 2007): “*An Opportunity to Achieve Real Change for Californians with ASD.*” The report is available at <http://senweb03.senate.ca.gov/autism/index.html>.

Senate Select Committee on Autism & Related Disorders (Senate ASD Committee)

Senate President Darrell Steinberg (Democrat – Sacramento) has recently announced the establishment of a new Senate Select Committee on Autism and Related. This Committee, which will be chaired by Senator Steinberg, has been authorized to implement the following:

- To provide a legislative forum for research, analysis, deliberations, and outreach in order to promote policies and legislation to better assist individuals with ASD and their families.
- To advance the work of the California Legislative Blue Ribbon Commission on Autism.
- To address the issues that were identified within the California Autism Legislative Package of 2007-2008;
- To deal with the fiscal challenges that confront the State in providing the necessary and crucial services for individuals with ASD;
- The Subcommittee shall submit its report to the Senate, including recommendations for appropriate legislation, no later than November 30, 2010, on which date it shall cease to exist.

Members of the Senate ASD Committee are:

- Senate President Darrell Steinberg (Democrat – Sacramento, 6th District) – Chair
- Senate Republican Leader Dennis Hollingsworth (Republican – Murrieta, 36th District)
- Sen. Elaine Alquist (Democrat – Santa Clara, 13th District),
- Sen. Roy Ashburn (Republican – Bakersfield, 18th District)
- Sen. Lou Correa (Democrat – Santa Ana, 34th District)

- Sen. Mark DeSaulnier (Democrat – Contra Costa, 7th District)
- Sen. Robert Dutton (Republican – Riverside, 31st District)
- Sen. Dean Florez (Democrat – Shafter, 16th District)
- Sen. Mark Leno (Democrat – San Francisco, 3rd District)
- Sen. Carol Liu (Democrat – Pasadena, 21st District),
- Sen. Alex Padilla (Democrat – Pacoima, 20th District)
- Sen. Fran Pavley (Democrat – Agoura Hills, 23rd District)
- Sen. Curren D. Price, Jr. (Democrat – Los Angeles, 26th District)
- Sen. Lois Wolk (Democrat – Davis, 5th District)

Focus of the Senate ASD Committee:

1. Early Identification & Intervention
 - Lifelong care can be reduced by 2/3rds with early diagnosis and intervention, which results in a cost savings to the State.
2. Insurance Coverage by Private Health Plans
 - Previous legislation last year (SB 1563 by Sens. Don Perata and Steinberg) was vetoed by the Governor, who indicated however that an administrative solution might be possible.
 - The issue of insurance coverage is covered under mental health parity and is also an issue of “equity and fairness”
 - The ASD Committee will work with the Schwarzenegger Administration to implement a possible administrative solution.
3. Transitional Training, Education & Employment
 - California spends, through the 21 non-profit regional centers, for adults with ASD is \$37,000 per year – dramatically higher than children with autism spectrum disorders, who have an average cost of \$9,800 per year.
 - Unemployment of 84% among regional center adults with developmental disabilities
 - California ranks 34th in the employment of persons with disabilities.
4. Issues Related to Housing for Individuals with ASD
 - 84% of persons with ASD in California are younger than 22 years.
 - Only 9% of persons with autism spectrum disorders live independently

Overarching Concepts of the Senate ASD Committee

- To establish an innovative and effective process by which the “voices of consumers, advocates, and family members can be heard.”
- To establish an infrastructure that promotes useful and productive, inclusive, collaboration and communication and seeks to “find common solutions and approaches” between individuals with ASD and individuals with other disabilities and special needs
- Focus on consumer-based concepts, which are dedicated to issues of equity and diversity, and also ensure that consumers, parents, & families as well as individuals working in the field must also be involved”

Strategic Approaches of the Senate ASD Committee:

- To establish a **network** of consumers, families, advocates, families, organizations, and other stakeholders that will work closely with the ASD Committee at the local and regional level in close collaboration with District Offices

- To provide an **exchange of information** (i.e. what's working; gaps and barriers; potential improvements; cost-effective strategies)
- To **promote events** that improve collaboration between ASD and other disabilities and special needs
- To provide **recommendations** that would be linked to the following:
 - The state should have a clear role and responsibility to address these issues
 - The solutions should be clearly identified, reasonable, and measurable, and
 - The solutions should have the potential to effect broad "systems change"
 - The solution would be feasible to implement during the current fiscal crises

Implementation Strategies of the Senate ASD Committee:

Senator Steinberg has indicated that the ASD Committee will soon establish a series of Task Forces and Working Groups that will work with persons with developmental disabilities, advocates and leaders throughout the state.

1. Establish **Regional Task Forces (RTF)** throughout the State that would be established by the Members' District Office (DO); but could also work with the DOs of other Senators who are not on the ASD Committee
2. The RTF would be appointed by the DO. Initial leadership team would be established and additional members would be included from the community. The RTF would be inclusive and diverse. The RTF could also partner and work with organizations affiliated with other disabilities and special needs.
3. The specific **goals and activities of the RTF** could include:
 - Establish an advocacy network (individuals, organizations, non-profits etc)
 - Establish and promote innovative approaches to improved communication; information sharing; and new partnerships.
 - Engage and involve local elected officials and policy makers
 - Provide information, strategic approaches, and best practices on effective models in the four topic areas
 - Identify gaps and barriers in existing services and delivery systems
 - Identify innovative funding streams &/or cost savings
 - Conduct Town Hall meetings and other "grass roots" community outreach activities.
 - Promote media coverage
4. Establish **State Coordinating Council for the Senate Select Committee on Autism & Related Disorders**. The specific goals and objectives of the State ASD Group could include the following:
 - Provide technical assistance, strategic planning, and assist in implementing a "work plans" for each of the RTFs.
 - Act as an information resource to the ASD Committee and RTFs
 - Coordinate the activities and recommendations of the RTFs
 - Assist the ASD Committee in activities related to federal issues

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The Demographics of Autism in California: Overview and Current Status

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- Autism Spectrum Disorders (ASD) is the fastest growing developmental disability in California and in the nation.
- Currently the ASD population that is served by the Dept. of Developmental Disabilities (DDS) in California is increasing at an average rate of 12% per year.
- During the past two decades there has been almost a twelve fold increase in autism rates in California
- In 1987 there were 1,701 individuals with ASD who were DDS consumers while in 2007 this number had risen to 34,656; an increase of 1,148 %.
- During this same time period, the other disabilities served by DDS have demonstrated a much smaller growth rate:
 - Mental Retardation (95%)
 - Cerebral Palsy (73%)
 - Epilepsy (66%)
- During this same time period California's populations increased by 27%
- Presently, the numbers of DDS consumers with Autism who are served by the Regional Center system (RC) now surpass the numbers of individuals with Cerebral Palsy and will soon surpass the numbers of individuals with epilepsy.
- In 2007 DDS served 5,575 adults with ASD and 31,376 children and youths under the age of 22 years
- Currently only about 6,000 adults with ASD are Regional Center (RC) consumers
- In the next 5 years more than 4,000 teenagers who have ASD will reach adulthood
- By 2018, estimated that there will be more than 19,000 adults with ASD in the RC system
- The adult population of adults with ASD served by the North Bay Regional Center (Napa from 19 to 57 consumers; Solano 102 to 246;

Sonoma 50 to 200) will triple within the next 10 years (from 173 in 2007 to 506 in 2017; the number of adults projected to increase by 36% in the next five years: from 173 in 2007 to 236 in year 2012.)

- Starting in the year 2013 there will be a sharp increase in number of adults with ASD who are RC consumers with a non-English primary language and will present a greater demand for culturally and linguistically appropriate services.
- Purchase of service (POS) by the RC for children (3-18) for children with ASD was \$6,993 as compared to \$3,447 for same group of children without ASD
- For consumers above the age of 19 years, the RC POS was \$26,047 for those with ASD as compared to \$15,935 for those without ASD
- RC POS for adults with ASD (over 22 years of age): average \$36,704; median \$31,482
- Number of individuals with ASD and mental retardation has dropped significantly and is now at 36%; as compared to an incidence of 79.6 in June 1987. This represents a 40% decrease in the classification of autism with mental retardation during the past 20 years
- Based on current trends there will be more than 50,000 RC consumers with ASD by September 2009.
- Based on current trends there will be more than 70,000 RC consumers with ASD by June 2012.
- Current estimates indicate that 75-80% of individuals with full spectrum autism as established by the DSM IV Classification are enrolled in the DDS service delivery system
- It has been estimated that DDS and the RC serve about 20% of all individuals who have some form (i.e. are considered to be on the spectrum) of ASD.
- Approximately 90% of parents with children who have ASD recognized an abnormality by 24 months of age
- Researchers indicate that 20%-30% of children experience "regressive form of ASD"
- From June 2002 to June 2007 the RC caseload for ASD increased by 70% (net growth of 14,279 consumers)
- The largest spike (four fold percentage increase) in the numbers of consumers with ASD served by the RC occurred from 1997 to 2002.
- Between 1990 and 2000, the California population increased by 13.8% while the ASD RC consumers increased by 359%; or by 26 times faster than the general California population.

- RC consumers with ASD increased by 1,110 percent over two decades, while the total number of DDS consumers increased by 136%.
- Breakdown of ages of RC consumers with ASD as of June 2007:
 - Mean age 13.6 years for all DDS consumers
 - 66% of the current RC consumers with ASD fall between the age of 2.6 to 24.6 years

The breakdown of these consumers is as follows:

- 12% between 0 to 4 years
 - 34% between ages 5 to 9 years
 - 23% between ages 10 to 14 years
 - 13% between ages 15 to 19 years
 - 6% between ages 20 to 24 years
 - 3% between ages 25 to 29 years
 - 3% between ages 30 to 34 years
 - 2% between ages 35 to 39 years
 - 2% between ages 40 to 44 years
 - 3% 45 years and older
- Place of Residence
 - DDS consumers with ASD who lived at home
 - 53% in 1987
 - 89% in June 2007 (30,673 individuals)
 - DDS consumers with ASD who lived in licensed community residential facilities
 - 31% in 1987
 - 7% in June 2007 (2,205 individuals)
 - DDS consumers with ASD who lived in Developmental Centers
 - 11% in 1987
 - 1% in June 2007 (354)
 - DDS consumers with ASD who lived Independently or Supported Living
 - June 2007: 754 individuals
- Consumers with ASD living at home as of June 2007:
 - 0 to 9 years of age: 12,102 individuals
 - 10 to 14 years of age: 7,663 individuals
 - 15 to 19 years of age: 4,062 individuals
 - 20 to 24 years of age: 1,517 individuals
 - 25 to 49 years of age: 1,533 individuals
 - 50 years and older: 76 individuals