Caring for Washington Individuals with Autism Task Force

Report to Governor and Legislature
Priority Recommendations and Implementation Plans
December 2007
Caring for Washington Individuals with Autism

December 2007

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Contents

Executive Summary

1 Chapter 1. Background and Introduction

3 Chapter 2. Autism Overview


7 Chapter 4. Priority Recommendation 1. Ensure all Individuals With ASD Receive Comprehensive Health Services and Coverage Within a Medical Home

11 Chapter 5. Priority Recommendation 2. Create a Statewide Coalition and Enhance Existing Regional Hubs

19 Chapter 6. Priority Recommendation 3. Screen All Children in Washington State for ASD Before the Age of Three Years; Ideally by Eighteen Months


27 Chapter 8. Priority Recommendation 5. Establish a Minimum of One Trained Autism Technical Assistance Specialist in Each of the Nine Education Service Districts


33 Chapter 10. Steering Committee

35 Chapter 11. Conclusion

Appendices

39 Appendix 1. Executive Summary From 2006 Caring for Washington Individuals with Autism Task Force Report

43 Appendix 2. Autism Task Force Members

Staff from the Washington State Department of Health

45 Appendix 3. Laws

51 Appendix 4a) Autism Task Force Subcommittee Members
54  Appendix 4b) Washington Coalition for Autism Spectrum Disorder and Related Disorders

65  Appendix 4c) Autism Task Force Report Identification/ Tracking/ Services Subcommittee

71  Appendix 4d) Autism Task Force Family Care Subcommittee Report

81  Appendix 4e) Autism Task Force Education Subcommittee Report

89  Appendix 4f) Steering Committee Legislative Information

97  Appendix 5. Task Force Recommendations

105 Appendix 6. Autism Task Force Fiscal Estimate

117 Appendix 7. Table Showing Current Regional Hubs

121 Appendix 8. Glossary

123 Appendix 9. Autism Task Force Acronyms

Bibliography
Executive Summary

In December 2006, the Caring for Washington Individuals with Autism Task Force (ATF) made recommendations to the Governor and Legislature about services needed for Washington individuals with autism spectrum disorder (ASD) and related disorders. The 2006 report included thirty one individual recommendations in four categories where change is needed: infrastructure, treatment, training, and funding.

The Washington State Legislature provided funds in the 2007-09 biennial budget to continue the ATF. The Legislature asked the ATF to develop implementation plans including cost estimates for its top priorities; develop an autism services guidebook for individuals with autism—birth through lifespan; and monitor federal autism legislation and grant opportunities. The ATF was asked to consider the context of broader developmental disabilities so that efforts would not be duplicated.

This report includes implementation plans and cost estimates developed by the ATF during mid-summer to early fall of 2007. The ATF selected six high level priorities to further develop during the very short time frame allotted for this task. Considerable thought and partnership went into the prioritization process and the work itself in order to develop a coherent and integrated strategy that takes into account the work of state agencies and community based organizations. The work includes beginning enhancement plans for system changes in family-centered care, education, training, and regional hubs. The ATF will continue to work on the "Washington Service Guidelines for Individuals with Autism—Birth through Lifespan" book and will monitor federal autism legislation and grant opportunities through June 2008.

The task force believes it is important to continue its work and provide guidance and input for planning and implementation of recommendations to meet the needs of individuals with ASD. The ATF’s role will likely change over time based on an expected evolution of work, but ongoing oversight is seen as important to achieve success in continuity of efforts. The cost to continue the Autism Task Force is approximately $211,031 per year.

This report considers the need for careful and deliberate planning, involvement of affected communities, and partnerships between public and private agencies.

As more is being learned about ASD and related disorders, our understanding about how to best serve the needs of these individuals will change. Thus, flexibility in the future is needed to address the changing needs of individuals with ASD and related disorders. We need to identify
and make use of future opportunities in funding, interventions, and support systems for families living with autism.

The ATF’s highest priority recommendations and cost estimates are:

**Ensure all individuals with ASD receive comprehensive health services and coverage within a Medical Home.**

Insurance mandates for evidence-based ASD services is the highest and most urgent priority of the ATF. Comprehensive health care within a Medical Home cannot be accessed without insurance coverage. Insurance that covers evidence-based services for ASD is severely lacking in Washington. A few employers in the state, including Microsoft, offer insurance coverage for families with ASD. A number of other states provide comprehensive health insurance benefits for evidence based services for autism and related disorders. (See chapter 4 details). The ATF hopes that Washington will learn from these successful models and implement needed changes in insurance coverage. With the time frame allocated, the ATF was unable to independently determine costs of comprehensive health services and coverage for evidence based services. Therefore, we recommend an analysis be done by the Department of Health through the sunrise review process under 48.47.030 RCW.

**Create and enhance existing area hubs** \(^1\) for ASD and related disorders in targeted areas of the state to 1) provide diagnostic services, therapies, and training for parents and professionals; 2) coordinate services currently available; and 3) address gaps in services.

In the time frame and funding for work given by the Legislature, the ATF has developed the vision of a network of hubs that collaborate and follow a statewide plan of common goals and standards for diagnosis, treatment, and services. Presently, there are five geographic regions with demonstration sites. They are all at various stages of development. None are complete in terms of containing all of the elements necessary for comprehensive health, education, and social care. The work related to developing these area hubs will be done by what is now being called the Washington Coalition for ASD and Related Disorders.

To begin enhancement of area hubs and achieve regional coordination, the ATF recommends two initial steps of work: 1) Forming and supporting a statewide coalition to continue planning. Detailed plans describe steps to create separate regional coalitions with associated demonstration sites (hubs). The statewide coalition will include regional representatives, and it

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\(^1\) The regional hub concept builds on the vision of the Regional Autism Centers of Excellence described in the 2006 ATF report
Priority Recommendations and Implementation Plans

will further refine the plan for enhancing and forming regional hubs. The estimated cost for the first year is $191,231 to fund a project coordinator and administrative support for the statewide coalition during the initial planning phase, which will include determining additional costs. 2) A recommendation for a detailed local assessment of regional resources/needs. This will provide definitive evaluation on present circumstances of each of the five hubs of Seattle/Tacoma, Spokane, Southeast Washington (Tri-Cities), Vancouver, and Yakima. Approximate costs to contract out for a complete community needs assessment for each hub are estimated at $270,218. (See details chapter 5).

Screen all children in Washington State for ASD before the age of 3 years, ideally by 18 months. To increase capacity, it is critical that all qualified health care providers and family resource coordinators be trained to administer the screenings. Screening, diagnosis, and referral to intervention for ASD must take place across the lifespan.

Adequate screening is dependent on health care providers’ and others’ abilities to recognize when an individual has characteristics of ASD or related disorders. Early recognition quickly facilitates an individual’s entry into services. A range of activities can be implemented to support this recommendation. A promotional statewide campaign, such as First Signs training, is recommended to encourage use of autism screening tools. Cost estimates for a promotional campaign represent three options and range from approximately $372,000 to $636,000 per year. (Refer to chapter 6 for details). This does not include costs for actual screening.

Provide family preservation services and strategies to help families of individuals with ASD stay together. When out-of-home placement is necessary, provide families with a variety of options that are age appropriate, offer ASD trained staff, and are in an environment designed to meet the needs of the individuals served.

Costs to increase the availability of five established family-centered care positions located in public and private ASD service organizations across the state serving individuals with autism is approximately $293,760 per year. (Refer to chapter 7 for details).

Establish a minimum of one trained autism technical assistance specialist in each of the nine Education Service Districts (ESD) to provide support to teachers and staff.

Hiring an ASD specialist within each Education Service District (ESD) provides meaningful collaboration between school districts and state agencies. This strategy supports both professionals and families. Having an expert close and available to all school districts means that families will not need to locate to another school district to receive services which are mandated by law, but not available. The ASD expert will build capacity within regions and
school districts that previously, due to geography or shortage of trained individuals, lack expertise in the field of autism and educational strategies and supports. Implementing this recommendation requires ongoing yearly costs of approximately $2.4 million. (Refer to chapter 8 for details).

Develop an Autism Services Guidebook that can be used as a resource directory for parents, organizations, and providers who serve individuals with ASD and their families, birth through the lifespan. Create an Autism Awareness license plate and use proceeds from the sale to promote programs benefiting individuals with ASD.

A request to draft the Guidebook was included in the 2007 budget proviso for the ATF. Creation of a license plate requires pursuing legislation in the first year of implementation. The task force did not assume a cost for pursuing legislation.
Chapter 1

Background and Introduction

In the 2007-09 biennial budget, the Washington State Legislature provided funds to continue the Caring for Washington Individuals with Autism Task Force (ATF). The ATF was created in 2005 to address growing concerns about Autism Spectrum Disorders (ASDs) in Washington State. In December 2006, the ATF submitted its first report and recommendations to the Legislature and Governor. In response to the first ATF report, the Legislature adopted the 2007-09 budget proviso and directed the ATF to:

- Review and continue to refine criteria for regional autism centers throughout Washington State based on community needs in each area, and address the role of autism centers within the larger context of developmental disabilities.
- Prioritize December 2006 recommendations and develop an implementation plan for the highest priority recommendations detailing how systems will coordinate to improve service and avoid duplication between state agencies including the Department of Social and Health Services (DSHS), Department of Health (DOH), Office of Superintendent of Public Instruction (OSPI), as well as school districts, autism centers, and local partners and providers. The plan shall also estimate the costs of the highest priority recommendations and report to the Legislature and Governor by December 1, 2007.
- Compile information for and draft the Washington Service Guidelines for Individuals with Autism - Birth through Lifespan book described in the task force’s recommendations. Funding to print and distribute the book is expected to come from federal or private sources.
- Monitor the Federal Combating Autism act and its funding availability and make recommendations on applying for grants to assist in implementation of the 2006 task force recommendations.

This report includes implementation plans and cost estimates for the top priorities selected by the ATF. The ATF will continue to work on the Washington Service Guidelines for Individuals with Autism—Birth through Lifespan book and monitor federal autism legislation and grant opportunities through June 2008.

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2 Executive Summary of Caring for Washington Individuals With Autism Task Force, 2006 Report, Appendix 1
3 2007 Substitute House Bill 1128 Section 222(21), Appendix 2
Chapter 2

Autism Overview

Autism is often grouped with similar disorders, all of which may be referred to collectively as autism spectrum disorders (ASD). “ASDs include autistic disorder, pervasive developmental disorder - not otherwise specified (PDD-NOS, including atypical autism), and Asperger syndrome. These conditions all have some of the same symptoms, but they differ in terms of when the symptoms start, how severe they are, and the exact nature of the symptoms. The three conditions, along with Rett syndrome and childhood disintegrative disorder, make up the broad diagnosis category of pervasive developmental disorders.”

As a group, ASDs are neurological developmental disabilities defined by significant qualitative impairments in: 1) social interaction, 2) language and communication, and 3) repetitive behaviors and preoccupations. It is common for individuals to have concurrent conditions and high healthcare use.

ASDs are considered habilitative, life-long conditions that are evident before the age of three years and persist throughout the life-span. Habilitative means individuals may improve with ongoing appropriate treatment and intervention. Without ongoing treatment and intervention, individuals will regress. There is no cure for ASD; however, research shows that children with ASD and related disorders are greatly helped if they receive appropriate early intervention.

Youth and adults with ASD and related disorders benefit immensely from ongoing appropriately designed environments, supports, and techniques that allow them to continue learning and to find meaningful work in the community.

Researchers have observed an increase in the proportion of children diagnosed with ASD in the past decade. It is not clear how much of the observed increase is because of improved diagnostic procedures and detection or because of a true rise in the number of cases. The most recent estimate from the Centers for Disease Control and Prevention (CDC) is that one out of every 150 children in the communities studied has an ASD. According to the CDC

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http://www.cdc.gov/ncbddd/autism/overview.htm


these conditions are more common than previously believed and should be treated as “urgent public health concerns.”

Thomas Insel, medical doctor and director of the National Institute of Mental Health states that autism and related disorders constitute the “fastest growing of developmental disabilities, affecting more children than Down Syndrome, childhood cancer, type 1 diabetes, and cystic fibrosis.” Estimates place the number of affected Americans at 1.5 million.

Treatment components for individuals with autism consist of education/special education, medical, biomedical and nonmedical care. Nonmedical care and support include transportation, child care and babysitting, respite care, out-of-home placement, home and vehicle modifications, and supported employment services. Medical and nonmedical costs to care for individuals with autism are high, with estimates of societal costs upwards of $90 billion annually. Cost-benefit analysis demonstrates the potential for substantial long-term cost savings to society if early and intensive behavioral interventions are provided.

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Chapter 3


Individuals with ASD often have co-existing diagnoses and related developmental disorders that may be best served by a cross agency system of health care, social, and educational services. This second report from the ATF boldly incorporates system change, integration, and coordination to avoid duplication across state agencies, higher education institutions, and organizations while calling on the state to meet its lawful obligations regarding education for all. This report includes implementation plans and cost estimates to facilitate decision making related to implementation of priority recommendations.

From the time the budget proviso became effective in July 2007, the task force had three and one half months to develop the content for this report. To accomplish the required tasks in that timeframe, the ATF formed four subcommittees and a Steering Committee. Subcommittees included 10 to 15 task force and community members. The four subcommittees were:

- Regional Networks (RN)
- Identification and Tracking (ID/T)
- Family Care (FC)
- Education (ED)

As a first step, the ATF identified a subset of the 31 recommendations described in the 2006 report for each subcommittee to review and prioritize. During subcommittee work, some of the original recommendations were combined. The subcommittees developed implementation plans and cost estimates for their selected highest priority recommendations and drafted reports summarizing their work. The ATF convened and reviewed the subcommittee reports. Ultimately, the ATF selected six recommendations to present as the highest

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11 Autism Task Force Subcommittee Members, Subcommittee Reports, Appendix 4
12 Task Force Recommendations, Appendix 5
13 Autism Task Force Subcommittee Members, Subcommittee Reports, Appendix 4
priorities. Public comment provided further clarification and input to the work. The implementation plans proposed by the subcommittees were revised and the final recommendations were adopted by the ATF on October 15, 2007.

The initiatives described here and the commitment of system partners to both the design and improvement of services, systems, and organizational structure will enhance the quality of life for the residents of Washington State with ASD and related disorders. The work involved is complicated and will take more than this one year to accomplish. Therefore the task force envisions a long-term plan to bring about change and foster new ideas. These recommendations are the beginning of the work process but constitute an integration of points for change within systems of family care, education, and training across health care, education, and social services.

The task force knows that orderly and efficient changes in infrastructure, treatment, and training are not immediate. The members feel it is important to provide continuity and guidance on the work. The ATF would like to continue to serve in its expert capacity. The task force’s role will change over time based on an expected evolution of recommendations, planning, and implementation of activities to meet the needs of individuals with ASD in the state. The estimated cost to continue the autism task force is approximately $211,031 per year.15

The Autism Task Force accomplished a significant amount of detailed work in the short time provided for the effort. The following chapters represent the implementation plans and cost estimates for the selected priority recommendations. Some priority recommendations do not have complete cost estimates because initial planning or additional work is necessary to determine costs of full implementation. Where possible, the ATF provides cost estimates for specific activities related to implementing the recommendations.16

14 Task Force Recommendations, Appendix 5
15 Autism Task Force Fiscal Estimate, Appendix 6
16 Details of all available cost estimates can be found in Appendix 6
Chapter 4

Priority Recommendation 1

Ensure all individuals with ASD receive comprehensive health services and coverage within a Medical Home.

Cost Estimates

Estimating costs for mandated insurance benefits would require a Sunrise Review by the Department of Health (48.47.030 RCW). The Caring for Washington Individuals with Autism Task Force will continue to explore the activities described in Objective 2 to increase access to medical homes for individuals with ASD and identify any related costs in the future.

Justification

The ATF chose to make mandating insurance benefits its first priority recommendation. Transforming the way insurance carriers include autism and related conditions within health insurance policy will significantly affect access for the majority of individuals with an autism spectrum or related disorder in our state.

Children with autism commonly have a range of medical conditions for which they need treatment. Nationally, 22 states have successfully mandated insurance coverage for evidence based intervention services that benefit children with autism. There is no mandate for insurance coverage within Washington State. Only four major private insurers in Washington offer any coverage for comprehensive services for children with autism. Only Microsoft, one of the four, is broad in benefit coverage. This could be a model for the state and industry. Many families have no coverage for needed services. This places families under tremendous financial burdens and strain to provide adequate care for their children. The Council for Affordable Health Insurance, in a 2007 report reviewing 10 states mandating insurance coverage, find the incremental cost of mandated benefits for autism at less than one percent.

19 Steering Committee Legislative Information, Appendix 4f
Appropriate, financially feasible services are not accessible for many individuals and families within their communities. Barriers to health care access include specific exclusions for autism diagnosis by many private health insurance plans, no coverage for Applied Behavioral Analysis (ABA) and other autism—related services, or denial of coverage for behavioral interventions by licensed PhD clinical psychologists or Board Certified Behavior Analysts (BCBA). All of these barriers contribute to access of care.

Wait-lists in the greater Seattle area typically exceed 6 months. Many families in our state have no access to services. To ensure that all individuals with autism and related conditions receive appropriate, accessible, and affordable services within their communities, insurance coverage for evidenced-based practices, including but not limited to, early intensive behavioral intervention is critical.

The task force believes that everyone deserves to have access to health care that follows sound evidence-based practices, and that the struggle for equality and recognition of autism and appropriate treatment will take both time and effort. Establishing good health policy takes thoughtful and considerate action to accomplish. As such, the task force recognizes that other priority recommendations such as training providers on new screening tools regarding autism may be more immediately attainable. These other steps are important for raising awareness and will help in the developing comprehensive health policy.

**Implementation Plan**

**Objective 1: Improve Insurance Coverage for Individuals with ASD**

1. Extend insurance benefits to cover interventions for individuals with ASD.
   a. Consult with individuals from states such as South Carolina and Pennsylvania where successful legislation mandating state insurance coverage for ASD intervention was passed.
   b. Mandate coverage of behavioral interventions provided by licensed PhD level clinical psychologists and Board Certified Behavior Analysts (BCBA).
2. Expand Medicaid benefits to promote equity in health care access and encourage providers to serve clients who are enrolled in Medicaid.

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Priority Recommendations and Implementation Plans

a. Increase the number of psychological assessments allowed (currently one per lifetime).
b. Increase rate of reimbursement and streamline paperwork and service approval process to encourage more providers to accept Medicaid patients.
c. Provide benefits comparable to private insurance, including reimbursement for costs of behavioral intervention.
d. Allow coverage of behavioral interventions provided by licensed PhD level clinical psychologists and board certified behavior analysts for individuals with an autism spectrum disorder.

3. Support policies that ensure neurodevelopmental therapy insurance benefits.
   a. Extend neurodevelopmental therapy benefit including speech-language services, occupational and physical therapy to individuals aged 18 years.
   b. Include certified behavioral analysts (BCBA) in neurodevelopmental therapy benefits.

Objective 2: Train and provide support to health care providers caring for individuals with ASD and increase access to medical homes.

The ATF recognizes that a medical home supports knowledge of and access to comprehensive services within the community. Providing increased support to health care providers is essential so that they have easily accessible, scientifically sound, reliable information about autism and related disorders. Health care providers need to be able to easily direct patients to the services they need. See Chapter 6 for additional activities to promote medical homes and increase provider knowledge of ASD and related disorders.

1. Improve advanced registered nurse practitioners, physician assistants, and medical school residency training on ASD and related conditions.
   a. Assess and provide training standards for Washington State programs.
   b. Collaborate with training programs to increase awareness and surveillance of autism and related conditions.
2. Identify an on-line medical consultation service to provide a quality consultation resource for primary care providers. Service could expand consultative service to primary care providers who serve individuals with autism. Promote use of the service across the state.  
3. Improve access to high-quality medical homes for individuals with ASD and related disorders.
   a. Explore successful programs nationally:
      i. Obtain consultation from the Waisman Center or similar organization.

23 Appendix 4c), Identification/Tracking Mid-Term Report
http://www.waisman.wisc.edu/nmhai/index.html
ii. Obtain assistance from the National Center on Medical Home Initiatives for Children with Special Needs at the American Academy of Pediatrics.\textsuperscript{25}
b. Explore regional successful medical home programs such as those available to the armed forces.
c. Make use of the Medical Home Leadership Network in Washington to pilot successful strategies to increase high quality medical homes throughout the state.\textsuperscript{26}
d. Use Child Health Notes\textsuperscript{27} as another possible model to provide more information about autism to primary care providers in Washington.


Chapter 5

Priority Recommendation 2

Create and enhance existing Regional Coalition Hubs (formerly Regional Autism Centers of Excellence) in targeted areas of the state to 1) provide diagnostic services, therapies, and training for parents and professionals; 2) coordinate services currently available; and 3) address gaps in services.

Cost Estimates

Enhancing existing ASD service hubs and creating new ones will be a multi year process. At this juncture, the ATF determined that funding is needed in the first year to form a statewide coalition and conduct regional needs assessments. The coalition will use the first year to create networks among existing regional hubs and build capacity to accomplish activities for years two and beyond. Year one activities include determining costs for activities in future years. The estimated costs for staffing the coalition in year one are approximately $191,231. This will support a project coordinator and administrative support for forming and coordinating the statewide coalition to be named, “Washington Coalition for ASD and Related Disorders.” It also includes travel and meeting expenses. (See Implementation Plan, Year One, step 1 a-e and Appendix 6 for details). Estimated costs for conducting regional needs assessments in year one are approximately $270,218. (See Implementation Plan, Year One step 2 a-b).

Justification

Autism is a complex disorder; however educational therapies, behavioral interventions, and some medications can provide major habilitation to individuals. 28 With appropriate services and supports, training, and information children on the autism spectrum may grow, learn, and thrive. Additionally, both family and educational institutions need helpful and active support so that individuals with autism spectrum and related disorders can reach their full potential. To improve services for families, the task force proposes creating regional hubs designed to serve individuals across their lifespan and incorporate clinical, family-centered care, early learning, education birth to 21, vocational training, and residential services. 29

29 Current Coalition Regional Hubs Table, Appendix 7
In this recommendation, the task force expands the concept of the Regional Autism Centers of Excellence to include autism spectrum and related disorders. Thus the name “Regional Autism Center of Excellence” is officially changed to “Washington Coalition of ASD and Related Disorders.”

This statewide coalition will be made up of ATF members and representatives from various organizations and agencies from the regional hubs. The coalition will help to anchor separate regional hubs and their own local coalitions. (A visual diagram of this concept has been provided in Appendix 7). The statewide coalition represents collaborative communication among the different regional hubs to implement and disseminate uniform standards regarding diagnosis and treatment. The purpose is to help the hubs increase capacity through regionally-relevant training, provider care, and referrals that are standardized and coordinated across the state. This begins the task of defining hubs and coordinating systems across regions of the state for comprehensive and culturally effective care and education for those with ASD and related disorders.

The initial stages for regional hubs already exist in several areas of the state:

- University of Washington Autism Centers (UW)—Seattle and Tacoma
- Northwest Autism Center—Spokane
- Children’s Village-Yakima Valley Memorial Hospital—Yakima
- Regional Autism Consulting Cadre, Autism Community Services—Vancouver
- Southeast Washington 3-River Autism Center, Autism Coalition, Autism Society of Washington/Tri-Cities Chapter, Neurological Resource Center—Tri-Cities

Each existing hub is unique as to the nature and extent of services provided and each has different capacities with respect to personnel and clients served. Only two of the existing centers now receive state funds (Seattle/Tacoma and Spokane). In various regions of the state access to diagnosis, treatments, educational, and vocational opportunities are incomplete. None of the centers offer diagnostic services for adults and therapeutic services for adults are limited.

All reflect a concentrated commitment to addressing the needs of individuals with autism spectrum disorders in their communities, and have already established themselves as a “hub” of service and/or resource provision for community members. These small seeds of excellence have been sown in different regions and are the beginning of the process of

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30 Caring for Washington Individuals With Autism Task Force 2006 report, Appendix 1
change. The task force recommends enhancing parts of these existing hubs and using them as demonstration sites for establishing new hubs in the future.

The task force identified goals for each regional hub and a working implementation plan toward those goals. The plan begins to define standards of care and envisions quality services beyond those available at this time. The statewide coalition work will be monitored by the ATF. Additionally, the task force believes the purpose of year one is to provide a more comprehensive, local site specific needs and resource assessment. The assessment will provide detailed information beyond the scope of the 2006 report, outlining gaps in services and variation in revenue and insurance availability within each region.

Each supported regional hub should work toward the following goals

1. Address regional gaps in service, training, and technical assistance.
2. Provide timely and coordinated services to families within their regions.
3. Partner with local Educational Services Autism Coordinator to provide professional training and technical assistance to local school districts through collaboration with the Autism Outreach Project.
4. Enhance regional capacity through professional training and technical assistance to community agencies, and providers.
5. Incorporate and disseminate best practice guidelines as determined by the Washington Coalition for ASD and Related Disorders.
6. Coordinate with existing supports and services to avoid duplication of services and enhance existing programs.
7. Identify regional and local partnerships to:
   a. Provide regional technical assistance and training.
   b. Disseminate screening and best practice parameters.
   c. Address gaps in regional service delivery.
   d. At a minimum, facilitate and provide diagnostic evaluation regionally within two months of referral.
8. Provide a plan for timely screening, referral, and consultation services for co-occurring medical and psychiatric conditions.
9. Prioritize family-centered care and outreach:
   a. Partner with local Department of Social and Health Services-Department of Developmental Disabilities-Family Resources Coordinators,\(^{31}\) Department of Health-

Children with Special Health Care Needs (CSHCN) program coordinators\textsuperscript{32} and Personal Agents for Adult Services.\textsuperscript{33}

b. As recommended by the Family-Centered Care and Identification subcommittees, the family should be contacted and linked to resources within 15 days of diagnosis.

c. Include development plan for system guide positions to provide support, direction, and a bridge to local and regional resources.

d. Partner with other local family-centered care, non-profit agencies and other organizations that foster encouragement and care to individuals with autism and related disorders.

\textbf{Implementation Plan}

\textit{Objective 1: Form a statewide coalition of regional hubs for autism spectrum and related disorders. The purpose is to maximize collective resources and ensure regional and community collaboration for state plan implementation, evaluation, and improvement.}

\textbf{Year One}

1. Build on the recommendations of the Autism Task Force and develop, refine, and implement a statewide plan for regional hubs.

a. Convene representatives to form the Washington Coalition for ASD and Related Disorders and begin preparation to enhance existing centers and expand hubs in future to new locations. The Coalition will be a subcommittee of the Autism Task Force. It will include ATF members as well as representatives from each identified hub, divisions within Department of Social and Health Services (DHS)\textsuperscript{34} such as Division of Developmental Disabilities (DDD), Division of Vocational Rehabilitation (DVR), and Mental Health Division (MHD); other agencies and organizations like Leadership Education in Neurodevelopmental and Related Disabilities (LEND),\textsuperscript{35} the Autism Society of Washington,\textsuperscript{36} the Arc of WA,\textsuperscript{37} public health hospitals, and others.

\begin{itemize}
  \item \textsuperscript{33} Available in some Washington State counties.
\end{itemize}
b. Rotate convener and leadership over time.

c. Hire a project coordinator and administrative support to work on the development and support of this statewide coalition.38

d. Develop a vision, mission, values, and principles as part of the statewide plan.

e. Engage regional hubs early in the process of developing and commenting on the statewide plan, regional hubs will then develop specific activities that move the plan forward for their areas.

2. Complete a needs assessment and fiscal analysis of gaps in services surrounding the five regional hubs.
   a. Document current local resources and gaps in services.
   b. Complete state level maps for those regions

**Year Two**

1. Engage regional and community coalitions and provide state mapping information to them to help identification of regional and community partners. Broadly disseminate the system maps.

2. Roll up individual regional hubs’ plans into the statewide coalition plan with regional priority-setting as part of its development.
   a. Share goals and objectives, but each region or community moves objectives forward in ways unique to its needs.
   b. Action steps of the plan are measurable and have regular updates of progress, including cause, barrier, and gap analysis when objectives are not met.
   c. Finalize and adopt the goals and objectives of the statewide plan with links to partner network/hub plans by identifying the activities their organizations are doing that move the shared goals and objectives forward.
   d. Based on the needs analysis described in year One, determine funding levels for each hub by:
      i. Developing cost analyses for regional hubs.
      ii. Use the existing Seattle-Tacoma and Northwest Autism Center regional hubs as two different models providing some similar services for cost analyses and staffing needs.
      iii. Tailor the cost analyses to regional service demands and resources.
   e. Establish partnerships with public hospital districts and established local agencies to meet rural needs.

3. Enhance existing regional hubs to initiate implementation of the statewide plan for autism spectrum and related disorders.

38 Fiscal Estimate Washington Coalition for ASD and Related Disorders, Appendix 6
a. Secure seed money for the Tri-Cities, Yakima, and Vancouver regional hubs to enhance or establish local infrastructure, support staff and consumer participation.

b. Provide increased funding for the existing hubs in Tacoma/Seattle and Spokane to enhance local infrastructure while expanding regional training, family support, and direct services.

c. Fund regional hubs through a Request For Proposal (RFP) process, which is to be determined.

4. The Washington Coalition for Autism Spectrum and Related Disorders will support the regional hubs and outreach to the local community.

a. Work toward securing funding for several regional hubs to meet established goals and vision.

b. Assess current involvement and activities in each region, and create detailed regional resource maps based on feedback from the regional coalition hubs.

c. Assure that inter-regional connections and shared tools and processes are initiated and practiced. For example, share best practices regarding screening tools and practices.

d. Partner with local universities to enable regional hubs to be conduits of information for providers and educators to build relationships with clinic partners, and to act as collaborative participants.

e. Maintain a web site and other communication mechanisms leveraging existing resources at the University of Washington.

**Years Three – Five and Ongoing**

1. Develop and implement a statewide coalition communication plan that brings together information about all of the resources and activities.

a. Connect with others who have done the work, network, and spread regional/community ideas.

b. Communicate the statewide plan to the leadership of partner organizations.

c. Disseminate initiatives and data reports to a broader scope of partners.

d. Hold an annual conference with focused small groups, or use technology opportunities to convene and share information.

e. Tie into other events, conferences, state and national events.

f. Establish media links for national events and efforts to reach nontraditional partners.

g. Support communication efforts by funding and hiring a dedicated person focused on communication plan implementation.

2. Evaluate the statewide coalition and regional hub process.

a. Evaluate the processes used to enhance and create regional hubs and have an evaluation plan in place for the new statewide plan that includes public, private, and community-based organizations and provides for qualified professionals who provide
evaluation. Costs associated with evaluation can not be determined at this time as the regional coalition process has not been established.
b. Identify specific clinical, outreach, and training goals for the future.
3. Develop and fund one to three additional network hubs in new regions of the state as identified by the statewide coalition.
Chapter 6

Priority Recommendation 3

**Screen all children in Washington State for ASD before the age of three years, ideally by 18 months.** To increase capacity, it is critical that all qualified health care providers and family resource coordinators be trained to administer the screenings. Screening, diagnosis, and referral to intervention for ASD must take place across the lifespan.

**Cost Estimates**

Cost estimates associated with conducting training, education, and media events to increase awareness of autism and provider knowledge range from approximately $372,000 to $636,000. The range represents three options; see Implementation Plan, step 4 below for details and recommended choice. Costs for planning and development of training and materials and work shops will be determined by the ongoing Caring for Washington Individuals with Autism Task Force and the Washington State Coalition for ASD and Related Disorders. These costs are not included here.

**Justification**

Services for individuals with ASD and their families are lacking in large part because of a shortage of adequate screening, diagnosis, and referral to existing services. There is a great need to increase awareness and expertise about ASD among providers as only about eight percent of primary care pediatricians screen for ASD’s. Additionally, specialty training in screening for autism is needed for service coordinators, Family Resources Coordinators (FRCs), and case managers. It is critical that providers also be knowledgeable about the full spectrum of ASD, including Asperger’s syndrome and PDD NOS (Pervasive Developmental Disorder - Not Otherwise Specified). Additionally, it is a priority recommendation to provide training to ensure that all children in Washington State are screened for ASD before the age three years, ideally by 18 months. Currently, there exists no comprehensive program within the state that can accomplish this goal within a timely manner.

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39 Fiscal Estimate for Training, Education, and Media to Increase Awareness of Autism and Provider Knowledge to Improve Screening for Autism, Appendix 6
Implementation steps include rolling out training to providers in the use of appropriate screening tools, early identification, and diagnosis. An organization such as First Signs\(^{41}\) can assist in implementation and provide a train the trainer model using local resources. There are few trained providers to diagnose and treat autism spectrum disorders and limited access to those who do. Availability of provider education is essential for building capacity in our state. Simultaneously, providing benefit coverage for approved treatments and interventions is essential to building needed capacity and access.

Because of the need for access to services, duplication of service provision to an individual with ASD is rare. This is because of a lack of awareness of autism, lack of available provider training and education around autism spectrum disorder, and lack of funding to implement appropriate service provision through existing agencies. Autism training and education requirements and opportunities are essential across disciplines to facilitate appropriate care for this population.

The implementation plan to improve screening for ASD and related disorders is presented in three levels. The options differ in the number of regional trainings, workshops, and mailings delivered each year. Also incorporated in each option are recommendations for improving access to and awareness of medical homes for individuals with ASD and related disorders (related to priority recommendation 1). These include: (1) developing web-based informational resources in the area of ASD for physicians and other health care providers, developed in partnership with Leadership Education in Neurodevelopmental and Related Disabilities (LEND)\(^{42}\) and others, and (2) revising and expanding the state medical home Web site to better address autism and related conditions. The ATF recommends upgrading the already existing Washington Medical Home Web site to include a special autism focus for health providers which can include links to screening and diagnosis, community based autism organizations, family support, state agencies, and navigation services.

**Implementation Plan**

**Objective 1: Increase provider awareness of and capacity to screen children for ASD and related disorders.**

**Year One**

1. Develop a plan specific to Washington to:

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a. Define and address the barriers to use of screening tools by physicians and other health care providers.
b. Develop an information and dissemination campaign.
c. Conduct regional trainings (including Continuing Medical Education credits).
d. Establish a dedicated resource page like that of First Signs web site.
e. Conduct an evaluation study.

2. Establish a workgroup to develop a plan for:
   a. Screening, diagnosis, referrals, and issues related to ASD in adolescence and adulthood.
   b. Identify training in use of screening tools to all primary referral sources including but not limited to, qualified health care providers, educators, service providers and case managers.
   c. Identify existing resources and cost of implementation.

3. Establish a second workgroup to evaluate and make recommendations pertaining to availability and use of appropriate screening tools, referral, and services for individuals with Asperger’s Syndrome and high-functioning autism, including identification of existing resources and cost of implementation.

4. Begin implementing training, education, and media plan. Contract with an organization such as First Signs that provides state-wide training on screening tools. The ATF recommends option two for $492,000.

5. Ensure recognition by Department of Social and Health Services Division of Developmental Disabilities (DDD) of Asperger’s Syndrome as an eligible disability.
   a. Provide training to DDD staff to assist higher functioning individuals with ASD.
   b. Provide training supports to DDD staff.

6. Ensure that children identified as possibly having an ASD are referred to services and a qualified professional that provides evaluation of autism spectrum disorders and related conditions.
   a. Refer to the Part C Infant Toddler, Early Intervention Program (DSHS, birth to three), or the local school district (over age three) for evaluation and, if eligible, appropriate services.
   b. Simultaneously, refer children to the local regional coalition hubs for information about qualified providers for diagnosis and other community based resources.

7. Collaborate with TRACE (Tracking, Referral, and Assessment Center for Excellence) whose purpose is to identify and promote the use of evidence-based practices and models

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44 Fiscal Estimate for Training, Education, and Media to Increase Awareness of Autism and Provider Knowledge to Improve Screening for Autism, Appendix 6
for improving child find, referral, early identification, and eligibility determination for infants, toddlers, and young children with disabilities.\textsuperscript{45}

Chapter 7

Priority Recommendation 4

Provide family preservation services and strategies to help families of individuals with ASD stay together. When out-of-home placement is necessary, provide families with a variety of options that are age appropriate, offer ASD trained staff, and are in an environment designed to meet the needs of the individuals served.

Cost Estimates

Costs estimates to enhance activities of five established family-centered care positions located in public and private service organizations serving individuals with autism are approximately $293,760 per year.46 (See Implementation Plan, Objective 2, Year One, Step One). Cost estimates for other activities are not included here and will be determined by the continuing ATF and the Washington State Coalition for ASD and Related Disorders.

Justification

Families who have a child or children with ASD are particularly vulnerable to stress and are often isolated and lacking an infrastructure of support.47 Family support is both a set of beliefs and approaches used to strengthen and empower families and communities. Supports that enable families to stay together and provide care for their loved ones with ASD within the home and community are critical and provide financial benefits for the state long term.

Family resilience is an outcome of family support, which enables families to deal with stress and increase their personal capacity to handle difficult medical and health conditions, as well as the needs of individuals who require educational and other services beyond what a typical developing individual requires. Family resilience is strengthened through culturally and linguistically effective family supports and social connection with other families who experience ASD. Support for families must address the optimal development of individuals with autism and related disorders, as well as typically developing children.

Implementation suggestions outlined here reflect the desire to build upon and expand the abilities of educators, health professionals, and families to best meet the unique needs of children and adults on the autism spectrum. Family-to-family care networks can improve the

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46 Autism Family Care Fiscal Estimate, Appendix 6
47 Family Care Mid-Term Report, Appendix 4d)
efficiency of care. Intact functioning families with access to appropriate expert care save money.

It is imperative that expansion across all systems take place in developing an effective family care infrastructure. Integration of care coordination services should build on existing Washington State autism specific support organizations. There are and should be multiple entry points for family care supports and services. Integration should take place with other supportive systems. These include Parent to Parent Networks, Fathers Network, the Family Resources Coordinators, Parent Coalitions, and other peer to peer support models found within the state. These models provide emotional and systems support for families of individuals with any developmental disability.

While autism specific organizations and programs know a great deal about ASD’s, this cannot be said for others providing emotional and systems support for all disabilities. The task force recognizes that all family support providers would benefit from ASD training. Neurological developmental disorders are complex by nature. A person answering phone calls and referring parents is expected to have a certain level of empathy which may be difficult without a certain level of knowledge on the subject.

Autism specific organizations need expansion of funding for staff positions; other parent support organizations need more funding for staff and training. Work plan objectives for the Washington Coalition for ASD and Related Disorders emphasize integrating family care and parent navigation of systems into the process of diagnosis and intervention as well.

The task force recommends implementing a statewide family care plan, building on the recommendations of the Autism Task Force, and integrating with existing programs in our state:

- Northwest Autism Center
- Autism Society of Washington
- Autism Outreach Project
- University of Washington Autism Center
- Parent to Parent Networks

A first step in this direction is to continue to expand the current phone support already established through the above mentioned organizations and agencies. Data shows that the need for these services far outpaces the number of staff hours currently provided.
Implementation Plan

Objective 1: Create a statewide Family Care Plan

1. Develop a vision, mission, values, and principles as part of the statewide plan for family care through the statewide coalition, Washington State Coalition for ASD and Related Disorders.

2. In conjunction with work of a Regional Coalition plan, assess regional resources and programs for assets and gaps.

3. Define the partnership model.

4. Develop a comprehensive plan for a “navigator” system within each region across the state to provide support and guidance.

5. Enhance regional and statewide capacity through partnerships and coalition. Work toward mission.

6. Identify networks unique to communities.


8. Coordinate with existing supports and services to avoid duplication of services and enhance existing programs.

9. Identify common work across related conditions, included with developmental disabilities.

10. Integrate work with all other subcommittee work.


Objective 2: Build capacity within ASD service agencies and organizations to serve families

Year One

1. Continue and enhance established phone support for families through resources such as the Autism Society of Washington help line, the University of Washington Autism Center help line, the Northwest Autism Center, the Autism Outreach Project and other organizations.

2. Encourage and back a DSHS partnership with schools on positive behavioral supports training.

Note: Current trends in the state show a resurgence in the admission of admitting children into institutions. Children are being placed out of home because of severe behavioral issues that families and community services are untrained to address. Though not all children with behavioral issues have a diagnosis of autism, behaviors are a common issue that families and school districts are struggling to address in a positive and appropriate ways. DSHS is developing a partnership with schools to help train and enhance all school workers with understanding of behavior as communication as opposed to behavior.
disruption or disobedience. The ATF will recommend this training for families when it has been established in the schools.

3. Encourage and back possible state legislation for a Developmental Disabilities Intensive In-home Services program through the Home and Community Based Service waiver. Note: New legislation is necessary to create a Developmental Disabilities (DD) Intensive In-home Services program through the Home and Community Based Service waiver, similar to the Children’s Intensive In-home Services (CIIS) program in Oregon. The program will directly address the issue of providing families with community services needed to keep their family intact and avoid costly out-of-home placement for the state. Intensive in-home services would be provided by a highly trained team of professionals. The team would help support the family and provide transition planning when they leave the program. They could deliver the services at home, in the school, and in the community. When out-of-home placement is necessary, families need to be provided with a variety of options that are age appropriate, offer ASD trained staff, and is in an environment designed to meet the needs of the individuals served.48

**Year Two**

Create a training DVD in partnership with UW Autism Center addressing intense behaviors. This DVD would be based on a program such as “Behavior As Communication” and useable to train parents and professionals. There are no cost estimates at this time on the training DVD.

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48 Family Care Mid-Term Report, Appendix 4d)
Chapter 8

Priority Recommendation 5

Establish a minimum of one trained autism technical assistance specialist in each of the nine Education Service Districts to provide support to teachers and staff.

Cost Estimates

Implementing this recommendation requires ongoing yearly costs of approximately $2.4 million.\textsuperscript{49}

Justification

As discussed in the December 2006 Caring for Washington Individuals With Autism Task Force report, “lack of ASD trained teachers and mentors in the school district creates great difficulty in implementing ASD programs and strategies…Best practices and successful strategies must be shared and made more widely understood; it is possible to develop and implement appropriate educational services and supports for each individual with ASD, through training of staff and utilization of already existing knowledge and best practices.”\textsuperscript{50}

The task force and Education subcommittee experts recognize that by creating a bridge position in the Educational Service Districts (ESD), it will be possible to serve many more individuals with ASD, as well as supporting the schools, local administrators, teachers, and staff in each of the nine districts.

Hiring an ASD specialist within each ESD region provides meaningful collaboration at the local level of school districts with state agencies and is recognized as supportive of both professionals and families. Having an expert close and available to all school districts means that families will not need to relocate to another school district to receive services which are mandated by law, but not available. The ASD expert will build capacity within regions and school districts that previously, due to geography or shortage of trained individuals, lack expertise in the field of autism and educational strategies and supports.

This position is currently active in Yakima (ESD 105) and Vancouver (ESD 112). The Autism Education Coordinator (AEC) in ESD 105 provides training to educators on ASD and education strategies, provides consultation to school districts on specific students, serves as a liaison to a birth to three agency and school districts, and provides other services as requested.

\textsuperscript{49} Autism Education Network Coordinator Fiscal Estimate, Appendix 6
\textsuperscript{50} Education Mid-Term Report. Appendix 4e)
The ESD112 Regional Autism Consulting Cadre Coordinator organizes technical assistance, training, workshops and conferences on ASD Educational Strategies and supports to school districts (Birth through Transition), Families, Community Agencies (C-Tran Transit System, Division of Developmental Disability Case Managers, Mental Health Providers, etc.) as well as Emergency Response. The Coordinator facilitates an Autism Cadre comprised of nine school districts (141 schools) and one Special Education Cooperative (18 rural schools) in Southwest Washington with 31 paying members. Each participating school district in the Cadre pays to have a school district staff member participate in this train-the-trainer model.

With funding, this recommendation is easily accomplished and will provide an immediate resource in multiple regions of the state while building on a program within the ESD system that has already been set with precedents in the Central and Southwest Washington regions. There are 296 school districts in the state; only twenty have a specialist with training specific to autism and related disorders. Infusing the districts with a train the trainer model using the ESD coordination system and a new connective position provides long term implications for standards of care and local capacity building which will be felt for generations. Additionally, using the already established Autism Outreach Project as lead and coordinator for the positions provides a statewide connection for dissemination of evidence-based practice of training.

Hiring outside consultants with expertise is costly to school districts as are the consequences of actions brought by parents against the districts because they are seeking appropriate services. An additional domino affect is felt when school districts turn to the state for answers and additional money for special education. Creating a position with built-in partnership and liaison with birth to three services and throughout the lifespan helps to establish common goals and objectives.

This is vital in caring for individuals and meeting federal and state initiatives such as:

- Individuals with Disabilities Education Act (IDEA) calls for appropriate educational opportunities for those with disabilities.\(^{51}\)
- No Child Left Behind requires parental involvement, highly-qualified teachers, scientifically based reading instruction, tutoring and supplemental educational services, and research-based teaching methods.\(^{52}\)

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Washington Learns, with three key components that align with several of the task force recommendations: 53

1) Full integration of our early learning, K–12 and post-secondary education systems so that the transition from one step to the next is seamless.
2) Ensuring all children thrive early in life and are prepared to enter school.
3) Ensuring all students master the skills they need to participate thoughtfully and productively in their work and their communities.

**Implementation Plan**

**Objective 1: Create and provide financial support for an Autism Education Network Coordinator or Regional Autism Consulting Cadre Coordinator in all nine Education Service Districts.**

**Year One and Ongoing**

1. Enhance and expand the present models of the Autism Education Network Coordinator/Regional Autism Consulting Cadre Coordinator to all nine regional state ESDs.
   a. Approximate cost of $2.4 million per year ongoing54
   b. Create a standardized job description
      i. Full time position (12 month calendar year)
      ii. Functions and responsibilities
         • Provide ongoing leadership, expertise, training and consultative services to school districts, birth to three agencies, early intervention agencies and other identified entities that support or necessitate the usage, identification and implementation of research based practices.
         • Develop infrastructure to facilitate increasing school districts, birth to three agencies, early intervention agencies and other identified entities capacity to serve children aged birth to 21 years with ASD and other related disorders.
      • The Autism Outreach Project55 will lead and collaborate with all nine ESD Autism Education Network Coordinators to identify statewide training needs and current gaps, develop training modules to address identified gaps and present trainings within each ESD. This will include ongoing collaboration with University of Washington, the Infant and Early Childhood Conference, and other training providers to avoid duplication of offerings.

54 Autism Education Network Coordinator Fiscal Estimate, Appendix 6
Caring for Washington Individuals with Autism Task Force

- Participate in local efforts to gather demographic data regarding children with autism. Report data gathered to the ATF Identification/Tracking subcommittee and the OSPI Autism Outreach Project.
- Continue to remain current in autism strategies, causation, incidence and prevalence, curriculums, methodologies, legal references and implications surrounding educational service and supports for students with autism and other related disorders.
- Conform to the principles, values and mission of each ESD.
Chapter 9

Priority Recommendation 6

**Develop an Autism Services Guidebook** that can be used as a resource directory for parents, organizations, and providers who serve individuals with ASD and their families, birth through the lifespan. **Create an Autism Awareness license plate** and use proceeds from the sale to promote programs benefiting individuals with ASD.

**Cost Estimates**

Funding for the ATF to draft the *Washington Service Guidelines for Individuals with Autism—Birth through Lifespan* book was given to the Department of Health in the 2007 state budget. The proviso specified that funding for printing and distributing would come from federal or private sources.

**Justification**

The Legislature instructed the Autism Task Force in 2007-2008 to “Compile information for and draft the *Washington Service Guidelines for Individuals with Autism—Birth through Lifespan* book described in the task force's 2006 recommendations.” Patterned after the *Ohio Service Guidelines for Individuals with ASD/ PDD Birth through Twenty-One*, this book will be relevant to families, educators, medical professionals, care providers, and others who will make informed decisions about individual care of children and adults with ASD and related disorders.

This guidebook is in its beginning stages. Including the words “Services Guidelines” in the title has been confusing as it causes people to think it is a resource guide of where to find services. That is not the intent. The book provides information across multiple arenas: the medical aspects of diagnostics and screening; identification of best practices regarding evidence based interventions; identification of essential components of instruction for students with autism and related disorders; community transition tips, family involvement and other helpful information similar to guidebooks created in Ohio. The task force will rename the book to incorporate and reflect the scope of the content. The task force intent is for the book to be available in both print and online form.

This manual will be written both by and for parents and professionals across education, medicine, and family-centered care for children, parents, and adults on the ASD spectrum. It will tell the reader how to use the book and help the individual navigate the various systems

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which overlap and intertwine when a person with autism or related disorders is diagnosed. The numerous essential components of the guidebook will provide significant supports for families and professionals. The ATF intends to provide a manual that incorporates the best practice standards for the state.

**Implementation Plan**

*Objective 1: Draft an Autism Services Guidebook for Washington State*

**Timeline: 2007-2008**

1. Contact Ohio Autism Task Force concerning guidebooks as guidance.
2. Compile information for the guidebook;
   a. Set process for compiling information
   b. Organize selected material
   c. Set process for writing
   d. Set process for review by ATF and public
3. Ensure information addresses multiple issues including:
   a. Birth through lifespan
   b. Community Transition
   c. Family Involvement
   d. Definitions
   e. Medical Aspects
   f. Educational Aspects
4. Research the federal Combating Autism Act, a Washington State autism awareness license plate, and other avenues for funding sources for the project.
Chapter 10

Steering Committee

Although not required under the 2007 budget proviso, some volunteer members within the Autism Task Force saw the need to create a Steering Committee to develop overall legislative strategies and provide consistent messages for improving Washington’s health, educational, and social services systems for individuals with autism and related disorders. The work has included best practices information and education to Legislators and the public about autism and related disorders and the effects of autism on children and their families if left untreated.

The relationship of people with autism spectrum disorders to the larger population of individuals with disabilities is of great concern to the Steering Committee. People with autism and related disorders can live healthy, happy, and productive lives in their communities if they are provided with the essential ingredients needed: trained teachers, doctors, caregivers, parents, and other professionals who provide services and supports; communities that are designed to be disability friendly; health insurance that provides adequate early intervention and related therapies, as well as comprehensive health care.

To accomplish its goal, the Steering Committee is working in partnership with other agencies, institutions, organizations, and advocates concerned about individuals with autism and related disorders. This includes a meeting with Governor Gregoire’s staff to hear feedback on the 2006 report and recommendations and to deliver a packet of timely documents concerning autism. Active exchange of information and expertise can establish a solid base for the working relationship between the Governor and the task force. This information will be shared with legislators and the public before the 2008 legislative session begins.

This exchange will help disseminate information to all other agencies and organizations in which integration of systems can and must occur. Collaborative efforts like these are positive and necessary to the process of change. Interest groups, similar to the Autism Task Force, are often well known for their ability to influence health policy because of pooled resources of knowledge about considerable problems and potential solutions to the issues. The Steering Committee is determined to raise awareness and help in highlighting where changes could occur in multiple systems. These kinds of changes and supports are beneficial not only for individuals with autism, but all citizens.
Chapter 11

Conclusion

The Caring for Washington Individuals With Autism Task Force is leading the way to a new understanding of the needs of Washington individuals with autism and related disorders. This new understanding is not unlike the understanding of how curb cuts and ramps for people with wheelchairs were once uncommon, and now are a part of the routine design of public buildings and community designs. Their benefit is felt not only by people in wheelchairs, but by elderly people who walk with a cane and cannot handle steps, as well as parents pushing strollers and others. Similarly, appropriate health care benefits, educational strategies, and sensitivity to the needs of individuals with autism leads to better health and educational environments for all children and youth, not just those who have been diagnosed with ASD and related disorders. Educating and supporting families so that they can provide care for their loved ones in their own homes is a priority. Reducing the need for costly and isolating institutionalization of individuals provides significant savings that can be used to support people in their own communities.

Systemic changes do not happen in a vacuum or come easily. They take considerable time and process modification across organizations to fill gaps. However, the task force believes that the efforts outlined in this beginning implementation plan will provide significant impact on the daily lives of families and individuals with autism and related disabilities.
Appendices
Appendix One

Executive Summary From 2006 Caring for Washington Individuals With Autism Task Force Report

Introduction

Autism Spectrum Disorder (ASD) is a developmental disorder that affects a person’s ability to communicate and relate to others. It is characterized by impairments in three domains: social interactions, language and communication, and repetitive behaviors and preoccupations. There is a wide variability in ASD symptoms and severity. It is often, but not always, accompanied by various degrees of sensory integration difficulty, speech delay, medical conditions, and motor involvement. IQs range from superior to severely mentally retarded. Twenty-five percent of people with ASD do not develop speech.

ASD affects as many as 1 in 166 children nationally. In Washington the rate is similar, estimated to be between 2-6 children per 1000. At this rate, almost every citizen of our state is likely to have a family member with ASD, know someone with ASD, or have some opportunity to deal with the issues posed by individuals with ASD. ASD is as common as juvenile diabetes, and more common than childhood cancer, Down Syndrome, deafness, or cystic fibrosis.

The Caring for Washington Individuals with Autism Task Force was created by law in 2005 to address the growing concerns about ASD in our state. The goal of the task force is to ensure that people with ASD are included in their communities and receive appropriate, timely, and legally required services throughout their life. Regardless of age, race, ethnicity, and geography, an individual with ASD needs individualized, evidence-based, culturally effective, multidisciplinary interventions, comprehensive health care, and community inclusion. ASD is a lifelong condition, and ongoing, appropriate treatments and culturally effective family supports are required to enable not only young children, but adolescents and adults with ASD, to live productive and healthy lives in their own communities.

The task force identified four areas where significant change needs to be made: Infrastructure (IN), Treatment (TT), Training (TG) and Funding (F). In all, the task force developed 31 recommendations within these categories.

Some of the task force recommendations will require long term systems changes. These changes include greatly increased access to comprehensive health care in a medical home, ongoing training of all types of professionals who work with individuals with ASD, fully
funded and culturally effective provider and family support services, and full funding of
regular and special education. Such systems improvements are essential and will benefit not
only individuals with ASD, but all people with disabilities. The problem of health disparities
based on race, ethnicity, and socioeconomic status is a critical issue which must be addressed
in our state. The recommendations in this report will assist in reducing health disparities.

**Essential Groundwork for Improving Autism Services**

The following six recommendations are essential first steps that should be taken immediately
to improve the system of care for individuals with ASD:

- Create regional autism centers of excellence in targeted areas of the state. These
centers of excellence will partner with universities and provide professional training
for educators, physicians, therapists, and other professionals who work with people
with ASD, increasing the capacity of Washington to provide ASD services at the
regional and community level. These centers will also assist in the coordination of
services currently available in the regions, provide diagnostic and treatment services
not readily available in some areas of the state and promote a medical home approach
to improving culturally effective, comprehensive health care.

- Increase Washington’s capacity to identify and track people with ASD and the services
they receive across their lifespan.

- Screen all Washington children for ASD before the age of three years, ideally by 18
months.

- Establish a minimum of one trained autism technical assistance specialist in each of
the nine Educational Services Districts (ESDs) to provide support to teachers and
staff.

- Ensure that state agencies already required to provide services to people with ASD will
have in place staff training on ASD and ASD supports.

- Create an autism services guidebook similar to the Ohio Services Guidelines for
Individuals with ASD. The task force recommends that Washington’s guidebook
include information and resources from birth through the lifespan.

**Next Steps: Implementation Planning**

The Governor should continue the task force for an additional two years to proceed with
implementing the six recommendations cited above. The purpose of the task force will
necessarily be modified to reflect a change of focus oriented toward implementation. In light
of this, the task force recommends adding new representatives to it, including individuals with
ASD, a representative of Washington Learns, an individual who can speak to transition, residency, and employment, representatives of regional hubs of autism activity in the state (Tacoma/Seattle, Spokane, Yakima, Tri-Cities, and Vancouver), and additional representatives representing diverse racial, ethnic, age, and other diverse perspectives.
Appendix Two

Autism Task Force Members

Sofia Aragon, JD, RN - Department of Health
Lauri Berreman, MS - Local School District Representative
Lou Colwell, EdD - Office of Superintendent of Public Instruction
Geraldine Dawson, PhD - University of Washington Autism Center
Monica Meyer - Education Services District
Felice Orlich, PhD - University of Washington Autism Center
Senator Marilyn Rasmussen - Senate Democratic Caucus
Senator Pam Roach - Senate Republican Caucus
Linda Rolfe, MSW - Department of Social and Health Services, Division of Developmental Disabilities
Ilene Schwartz, PhD - University of Washington
Dawn Sidell, RN, BSN - Northwest Autism Center
Diana Stadden - Autism Society of Washington
Carolyn Taylor, MS - Autism Outreach Project
Representative Maureen Walsh - House Republican Caucus
Representative Brendan Williams - House Democratic Caucus

Staff from the Washington State Department of Health

Maria Nardella, MA, RD, CD - Children with Special Health Care Needs
Carol L. Miller, MPH - Children with Special Health Care Needs
Candi Wines, MPH - Office of Maternal and Child Health
Riley Peters, PhD - Office Director, Office of Maternal and Child Health
Leslie Carroll, MUP - Children with Special Health Care Needs
Jane Berube - Children with Special Health Care Needs Autism Support
Appendix Three

Laws

a) **Substitute House Bill 1128 Proviso Language**

SHB 1128 Chapter 522 Laws of 2007 Section 222(21)

$100,000 of the general fund--state appropriation for fiscal year 2008 is provided solely to continue the autism task force established by chapter 259, Laws of 2005, through June 30, 2008. The task force shall:

(a) Review and continue to refine criteria for regional autism centers throughout Washington state based on community needs in each area, and address the role of autism centers within the larger context of developmental disabilities;

(b) Prioritize its December 2006 recommendations and develop an implementation plan for the highest priorities. The plan should detail how systems will coordinate to improve service and avoid duplication between state agencies including the department of social and health services, department of health, office of superintendent of public instruction, as well as school districts, autism centers, and local partners and providers. The plan shall also estimate the costs of the highest priority recommendations and report to the legislature and governor by December 1, 2007;

(c) Compile information for and draft the "Washington Service Guidelines for Individuals with Autism - Birth Through Lifespan" book described in the task force's recommendations. Funding to print and distribute the book is expected to come from federal or private sources; and

(d) Monitor the federal combating autism act and its funding availability and make recommendations on applying for grants to assist in implementation of the 2006 task force recommendations. The department of health shall be the lead agency in providing staff for the task force. The department may seek additional staff assistance from the office of the superintendent of public instruction and the committee staff of the legislature. Nonlegislative members, except those representing an employer or organization, are entitled to be reimbursed for travel expenses.
b) **Senate Bill 5311: Chapter 259, Laws of 2005**

CERTIFICATION OF ENROLLMENT

**SENATE BILL 5311**

Chapter 259, Laws of 2005

59th Legislature
2005 Regular Session

**AUTISM TASK FORCE**

**EFFECTIVE DATE: 7/24/05**

Passed by the Senate April 16, 2005
YEAS 42 NAYS 0

BRAD OWEN
President of the Senate

Passed by the House April 5, 2005
YEAS 95 NAYS 0

FRANK CHOPP
Speaker of the House of Representatives

Approved May 4, 2005.

CERTIFICATE

I, Thomas Hoenemann, Secretary of the Senate of the State of Washington, do hereby certify that the attached is **SENATE BILL 5311** as passed by the Senate and the House of Representatives on the dates hereon set forth.

THOMAS HOEMANN
Secretary

FILED

May 4, 2005 - 1:37 p.m.

CHRISTINE GREGOIRE
Governor of the State of Washington

Secretary of State
State of Washington
SENATE BILL 5311

AS AMENDED BY THE HOUSE

Passed Legislature - 2005 Regular Session

State of Washington 59th Legislature 2005 Regular Session

By Senators Rasmussen, Jacobsen, McAuliffe, Mulliken, Stevens, Roach, Shin, Kohl-Welles and Spanel

Read first time 01/20/2005. Referred to Committee on Health & Long-Term Care.

1 AN ACT Relating to creating an autism task force; and creating new
2 sections.

3 BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF WASHINGTON:

4 NEW SECTION. Sec. 1. The legislature finds that:
5 (1) Autism is a complex developmental disability that typically
6 appears during the first three years of life;
7 (2) As many as one million five hundred thousand Americans are
8 believed to have some form of autism;
9 (3) The number of children with autism is increasing;
10 (4) Autistic behaviors not only make life difficult for people with
11 autism but also make life hard for their families, health care
12 providers, and teachers;
13 (5) Families coping with this devastating illness are searching for
14 answers about its causes, diagnosis, prevention, and treatment;
15 (6) Presently, there is no effective means to prevent, fully treat,
16 or cure the disorder;
17 (7) Early intervention is critical for affected children to gain
18 maximum benefit from current therapies;

p. 1  SB 5311.SL
(8) Strategies about how to best prevent, identify, treat, and accommodate the needs of individuals with autism and their families are urgently needed.

NEW SECTION. Sec. 2. (1) The caring for Washington individuals with autism task force is created to study and make recommendations to the legislature regarding the growing incidence of autism and ways to improve the delivery and coordination of autism services in the state.

(2) The task force shall consist of fourteen members: Four members of the legislature, including two members of the senate appointed by the president of the senate, one of the majority party and one of the minority party, and two members of the house of representatives appointed by the speaker of the house of representatives, including one of the majority party and one of the minority party; and ten additional members appointed by the governor, who shall include at least:

(a) Two parents of children with autism;
(b) A representative of the autism center at the University of Washington;
(c) A representative of the department of health;
(d) A representative of the department of social and health services;
(e) A representative of the office of the superintendent of public instruction;
(f) A representative of a local school district;
(g) A representative of an educational service district; and
(h) An expert in the field of early intervention services.

(3) The task force shall:

(a) Review the available literature and consult with experts to gain an understanding of the causes of the disorder and its incidence in Washington;
(b) Assess the availability of services currently provided for early screening, diagnosis, and treatment of the disorder;
(c) Assess the availability of services to assist families of individuals with autism;
(d) Review the effectiveness of programs and services provided to individuals with autism and their families;
(e) Review other issues and concerns that the task force believes would be helpful in arriving at sound policy recommendations; and
(f) Complete its review and submit its recommendations to the appropriate policy and fiscal committees of the legislature and the governor by December 1, 2006.

(4) The department of health shall be the lead agency in providing staff needed for the performance of the work of the task force. The department may seek additional staff assistance from the office of the superintendent of public instruction and the committee staff of the legislature.

(5) Legislative members of the task force shall be reimbursed for travel expenses in accordance with RCW 44.04.120. Nonlegislative members, except those representing an employer or organization, are entitled to be reimbursed for travel expenses in accordance with RCW 43.03.050 and 43.03.060.

Passed by the Senate April 16, 2005.
Passed by the House April 5, 2005.
Approved by the Governor May 4, 2005.
Filed in Office of Secretary of State May 4, 2005.
Appendix Four

4 a) Autism Task Force Subcommittee Members

Regional Networks
Co-chair: Monica Meyer - Education Services District
Co-chair: Felice Orlich, PhD - University of Washington Autism Center
Linda Barnhart, ARNP, MSN - Department of Health, Children with Special Health Care Needs
Lauri Berreman, MEd - Local School District Representative
Terry Buck, BS Ed - DSHS/Division of Developmental Disabilities
Cindy Carroll - Children’s Village, Yakima Valley Memorial Hospital
Sue Elliott - The Arc of Washington State
Arzu Forough - Autism Speaks Advocacy chair
Erin Lynch - Autism Society of Yakima/Parent
Carol L. Miller, MPH - Department of Health, Children with Special Health Care Needs
Senator Marilyn Rasmussen - Senate Democratic Caucus
Linda Rolfe, MSW - Department of Social and Health Services, Division of Developmental Disabilities
Ronda Schelvan, MEd - Washougal School District
Ilene Schwartz, PhD - University of Washington
Dawn Sidell, RN, BSN - Northwest Autism Center
Diana Stadden - Autism Society of Washington
Carolyn Taylor, MS - Autism Outreach Project
Glenn Tripp, MD - Mary Bridge Children’s Hospital

ID/Tracking
Co-chair: Geraldine Dawson, PhD - University of Washington Autism Center
Co-chair: Nancy Simon, MD, MPH - University of Washington Medical Center
Jane Campbell, MS – King County Developmental Disabilities Division
Victoria T. Crescenzi, MD - Bremerton Naval Medical Center, State Interagency Coordinating Council
Kathrin Fortner, BS - Holly Ridge Center
Katie Hutchinson, PhD - Department of Health, Maternal and Child Health Assessment
Carol L. Miller, MPH - Department of Health, Children with Special Health Care Needs
Felice Orlich, PhD - University of Washington Autism Center
Kate Orville, MPH - Washington State Medical Home Leadership Network
Carolyn Taylor, MS - Autism Outreach Project
Samuel H. Zinner, MD - Center on Human Development and Disability

Family Support
Co-chair: Dawn Sidell, RN, BSN - Northwest Autism Center
Co-chair: Diana Stadden - Autism Society of Washington
Crystal Blanco - Parent
Don Burbank - Parent
Leslie Carroll, MUP - Department of Health, Children with Special Health Care Needs
Tracie Day-Hoppis - Children’s Village, Yakima Valley Memorial Hospital
Angela Dawson - King County Parent to Parent
Sue Elliott - The Arc of Washington
Debra Finck, MA - Northwest Autism Center
Arzu Forough - Autism Speaks Advocacy Chair
Patty Gee, MEd - Autism Society of Washington
Alan Gill - Families for Early Autism Treatment
Sally James - Parent
Erin Lynch - Parent
Carol L. Miller, MPH - Department of Health, Children with Special Health Care Needs
Lance Morehouse - The Arc of Washington
Cami Nelson - Parent
Felice Orlich, PhD - University of Washington Autism Center
Helen Powell - Aspergers Support Network
Carolyn Taylor, MS - Autism Outreach Project

Education
Co-chair: Lauri Berreman, MEd - Local School District Representative, ESD 105 Autism Education Coordinator
Co-chair: Carolyn Taylor, MS - Autism Outreach Project
Monique Bartoldus - Holly Ridge Center
Alison Clark, Med - West Valley School district
Lou Colwell, EdD - Office of Superintendent of Public Instruction
Arzu Forough - Autism Speaks Advocacy chair
Linda Hawkins - Bellevue School District
Shelly Marquett - East Valley School District
Monica Meyer - Education Services District
Gretchen Schmidt Mertes, MEd - Bethel School District
Carol L. Miller, MPH - Department of Health, Children with Special Health Care Needs
Linda Rolfe, MSW - Department of Social and Health Services, Division of Developmental Disabilities
Nancy Rosenburg, MS - University of Washington
Ilene Schwartz, PhD - University of Washington
Ronda Schelvan, MEd - Washougal School District
C. Milani Smith, PhD - University of Washington Autism Center

Steering Committee
Co-chair: Monica Meyer - Education Services District
Co-chair: Diana Stadden - Autism Society of Washington
Geraldine Dawson, PhD - University of Washington Autism Center
Carol L. Miller, MPH - Department of Health, Children with Special Health Care Needs
Felice Orlich, PhD - University of Washington Autism Center
Senator Marilyn Rasmussen - Senate Democratic Caucus
Senator Pam Roach - Senate Republican Caucus
Dawn Sidell, RN, BSN - Northwest Autism Center
Carolyn Taylor, MS - Autism Outreach Project
Representative Maureen Walsh - House Republican Caucus
Representative Brendan Williams - House Democratic Caucus
4 b) Washington Coalition for Autism Spectrum Disorder and Related Disorders Report

(Formerly Regional Network Subcommittee)

October 1, 2007

Regional Networks Subcommittee Members

Co-chair: Monica Meyer - Education Services District
Co-chair: Felice Orlich, PhD - University of Washington Autism Center
Linda Barnhart, ARNP, MSN - Department of Health, Children with Special Health Care Needs
Lauri Berreman - Local School District Representative
Terry Buck, BSEd - DSHS/Division of Developmental Disabilities
Cindy Carroll - Children’s Village, Yakima Valley Memorial Hospital
Sue Elliott - The Arc of Washington State
Arzu Forough - Autism Speaks Advocacy chair
Erin Lynch - Autism Society of Yakima/Parent
Carol L. Miller, MPH - Department of Health, Children with Special Health Care Needs
Senator Marilyn Rasmussen - Senate Democratic Caucus
Linda Rolfe, MSW - Department of Social and Health Services, Division of Developmental Disabilities
Ronda Schelvan, MEd - Washougal School District
Ilene Schwartz, PhD - University of Washington
Dawn Sidell, RN, BSN - Northwest Autism Center
Diana Stadden - Autism Society of Washington
Carolyn Taylor, MS - Autism Outreach Project
Glenn Tripp, MD - Mary Bridge Children’s Hospital

Subcommittee Work Plan

Goal 1: To refine the criteria for a regional network

1. Regional networks will be established leveraging existing resources throughout the state. Each network will:
   a. Assess regional gaps in service, training and technical assistance
   b. Provide timely and coordinated services to families within their local region,
   c. Enhance regional capacity through professional training and technical assistance to schools, community agencies and providers,
   d. Incorporate and disseminate best practice guidelines as determined by a consortium of WA state regional networks
   e. Coordinate with existing supports and services to avoid duplication of services and/or enhance existing programs
   f. Networks will seek funding through an RFP (Request Funds Proposal) process. The coordinating agency may be the Department of Health.
   g. Funding level for this RFP is to be determined.
      i. Fiscal note to complete cost analysis for 6 regional networks
ii. Use the existing Seattle-Tacoma regional center as a model for cost analysis/staffing needs
iii. Tailor this cost analysis to regional service demands and resources
iv. Consider partnerships with public hospital districts to meet rural needs.

2. Each proposed regional network will:
   a. Identify regional and local partnerships to
      i. Provide regional technical assistance and training
      ii. Disseminate screening and best practice parameters
      iii. Address gaps in regional service delivery
      iv. At a minimum, facilitate and provide diagnostic evaluation regionally within two months of referral
      v. Please see appendix for specific clinical criteria
   b. Identify infrastructure necessary to support the RTN (Regional Training Networks) criteria
   c. Provide a plan for timely screening, referral and consultation services for co-morbid medical and psychiatric conditions
   d. Prioritize family support and outreach
      i. Partner with local family resource coordinators and CSHCN (Children with Special Health Care Needs)
      ii. Integrate family support and ID tracking goals for contact within 15 days of diagnosis
      iii. Include plan for parent navigators to provide support, guidance and a bridge to local/regional supports already in existence

Goal 2: A statewide coalition of the 6 regional networks will be created to maximize collective resources and to ensure regional and community collaboration for state plan implementation, evaluation and improvement.

Timeline Year One
Objectives

1. Build statewide and regional coalitions to initiate and coordinate autism and related conditions- activities on the state, regional, and local levels.
   a. Convene an initial planning committee for forming a statewide coalition.
   b. Be clear about the coalition’s purpose, including having the statewide coalition oversee the statewide plan and coordinate efforts, lead partnership development, identify incentives, and a share leadership role with communities.
      i) DOH would act as a convener, but over time, leadership could be rotated or placed elsewhere, such as at the University of Washington.
      ii) Establish and fund a State Coordinator Position to work with the planning committee on the formation of a statewide coalition. See fiscal note in Appendix
   c. Develop structure (large group or executive committee), roles, and responsibilities of members.
   d. Combine regional and sector representation on the statewide coalition, and maintain a representative steering group with everyone having equal vote,
      i) Identify existing DOH (Department of Health) coalitions,
      ii) Engage the ADA (Americans with Disabilities Act).
   e. Determine how to staff and finance the process and do the work.
Timeline Year Two

f. Initiate a process to create 6 regional networks using the hub concept. Identify regions by grouping counties that cluster with an urban core, and spread access to resources out to rural and remote areas (look at existing regions used by DOH programs and care seeking patterns of the population).
   i) Existing area resources will be leveraged and provide “home” for each network.

g. Identify partners in regional and community efforts (e.g., schools, health districts) and engage people not now engaged, including consumers.
   i) Identify regional conveners.

h. Support coordination efforts by funding and hiring a dedicated person focused on coordination of regional networks and implementation processes.
   i) Create a coordinating position
   ii) Possible funding through RFP process

2. Implement a statewide plan, building on the recommendations of the Autism Task Force that is shared by the regional networks.
   a. Develop a vision, mission, values, and principles as part of the statewide plan.
   b. Engage regional coalitions early in the process of developing and commenting on the statewide plan, regional networks then develop specific activities that move the plan forward.
   c. Investigate the use of cause/effect facilitation to set priorities and use of a logic model to develop further all objectives in the statewide plan.
   d. Regional network plans roll up to the statewide plan with regional priority-setting as part of its development.
      i) As in AIDS Net or asthma initiative models, link state and regional or community activities with different activities at each level that link to the whole.
      ii) Share goals and objectives, but each region or community moves objectives forward in ways unique to its needs.
   e. Action steps of the plan are measurable and have regular updates of progress, including cause, barrier, and gap analysis when objectives are not met.
   f. Finalize and adopt the goals and objectives of the statewide plan with links to partner plans by identifying the activities their organizations are doing that move the shared goals and objectives forward.
   g. Finalize, implement, monitor, and revise the statewide plan.

3. Develop the system mapping process, identify new partners, and invite them into the process: Complete a needs assessment

Timeline Year Three-Four

a. Document what resources we have now and who is doing what.

b. First complete state level maps, then look at regional and community coalitions, and provide state mapping information to them to help them identify regional and community partners.

c. Broadly disseminate the system maps.

4. Identify resources that will support regional/community coalitions.
   a. Regional networks will assess current involvement and activities in each region, and have regional resource maps based on statewide maps.
b. Assure that inter-regional connections and shared tools and processes are initiated and practiced (e.g., screening).

c. Secure seed money for regional networks to establish local infrastructure, support staff and consumer participation, among other needs.

d. Partner with local universities to enable regional networks to be conduits of information for providers and educators to build relationships with clinic partners, and to act as collaborative participants.

e. Maintain a website and other communication mechanisms leveraging existing resources at the University of Washington

5. Develop and implement a statewide coalition communication plan that brings together information about all of the resources and activities.

a. Connect with others who have done the work, network, and spread regional/community ideas.

b. Communicate the statewide plan to the leadership of partner organizations.

c. Disseminate initiatives and data reports to a broader scope of partners (see Goal #1).

d. Hold an annual conference with focused small groups, or use technology opportunities to convene and share information.

e. Tie into other events, conferences, and state and national events.

f. Establish media links for national events and efforts to reach nontraditional partners.

g. Support communication efforts by funding and hiring a dedicated person focused on communication plan implementation

6. Evaluate the statewide coalition and regional network process itself to see if it has made a difference.

a. Evaluate the 2007-2008 plan and have an evaluation plan in place for the new statewide plan that includes public, private, and community-based organizations and provides for an academic evaluation

b. Identify specific clinical, outreach and training goals

7. Create an anticipatory planning process for new opportunities and emergent problems within DOH, across programs and with other partners (e.g., the state Office of Superintendent of Public Instruction).

a. Assure that the planning process has the flexibility to address a situation that “bends the rules.”

Key Ideas and for Future Consideration:

- Include everyone interested in participating, expand membership, and identify new entities and partners.
- Consider establishing a future DOH autism and related conditions advisory board, possibly with condition-specific subgroups.
- In the statewide coalition, start with a focus on autism, but make clear that the long-term intent is to focus on developmental disabilities and related conditions and integrate efforts. Each region would move toward this integration at the pace that works in its group.
- Assure representation of diverse populations, so the system works to reduce barriers.
- Establish a statewide website as an opportunity to comment and review documents, CDC (Centers for Disease Control) links, etc. Focus on communication rather than meetings and committees; use creative technology.
- Encourage collaboration with other coalitions.
- Encourage collaboration with non-traditional partners.
- Maximize private and community partnerships, including businesses.
- Build a sense of being part of larger system, connected, with a common vision.
- Assure access to shared resources, maximize resources (people, money), and reduce duplication,
- Assure access to shared knowledge, information, and data.
- Encourage shared decision-making and evaluation.
- Seek expanded resources for the system.
- Provide clear definitions.
- Be aware of regional/community differences in focus of work.
- Define the partnership model.
- Use evidence-based interventions.
- Identify networks unique to communities.
- Create an informed citizenry making good choices.
- Bring in the private practice community that is not part of larger delivery systems.
- Look ahead to the community eventually mobilizing itself, building community capacity and coalitions.
- Identify common work across related conditions, such as developmental disabilities.

**Appendix A: Clinical goals for regional network**

Each regional network will collaborate with local resources and community providers to increase access to timely and evidence based diagnostic, behavioral and medical services for individuals with Autism and related conditions. Currently, the greater Puget Sound region provides the majority of diagnostic services for the state. A more significant dearth of services exists beyond the greater Puget Sound area, creating significant barriers to behavioral and medical interventions for this population. As a result, lengthy wait lists are the standard within the existing centers in Tacoma and Seattle preventing timely diagnosis. Moreover, once a diagnosis is received, access to services and supports outside of the greater Puget Sound area is severely compromised creating a substantive hardship for these individuals and their families. The regional network model aims to ameliorate these health disparities through provision of coordinated and culturally relevant best practices, training and technical assistance to the local community, family support and outreach.

To reach the goal of best practice, each network should partner with local resources to form multidisciplinary diagnostic teams, behavioral intervention and consultation teams, and medical consultation teams. All team members should have specific training and expertise to serve individuals with Autism and related disabilities.

**Multidisciplinary diagnostic teams should include:**
- Psychology
- Developmental Pediatrics
- Speech therapy
- Occupational therapy/Physical therapy
- Social work

**Behavioral intervention teams across the lifespan should include:**
- Psychology
- Behavioral interventionists (1 PhD level BCBA and # masters based on regional need)
- SLP
- OT/PT
Medical teams should include
Psychiatry
Nurse coordinator
Sleep medicine specialist
Gastroenterology
Neurology

Regional Networks Agencies and Partnerships
State Agencies (and ‘sub’s)
DSHS-State
DSHS-Regional Offices
DDD State
Division of Developmental Disabilities Administrators
DDD in counties
DVR in areas
DSHS-part C –Family Resource Coordinator’s
Developmental Disability Centers
CPS-Child Protective Services
OSPI
OSPI Special Education
DSHS/Mental Health Division
Autism Outreach Project
CSHCN state
Office of the Insurance Commissioner
State Interagency Coordinating Council Members
State Interagency Coordinating Council Committees Members
Department of Early Learning
LEND

Other Government Agencies (and ‘sub’s)
County Health Districts or Departments
Children with Special Health Care Needs Coordinators (CSHCN) by county
Feeding Teams
Head Start
Early Head Start
County Interagency Coordinating Council Chairs
Educational Service District (ESD) Coordinators
Educational Service District (ESD) Special Education
School District’s Boards of Education
Leadership Education in Neurodevelopmental and Related Disabilities (LEND)
Legislators in area

Other
Tribes
Medical association
Parent to Parent Coordinators (Network)
Father’s Network
Arc of Washington (all different)
16 Neurodevelopmental Centers
Family Voices
Elk’s therapists
Families for Effective Autism Treatment (FEAT)
Medical Home Network
Autism Society of Washington
Autism Advocates
Autism Speaks
Developmental Disabilities Council
Mental Health Transformation Project
Community Connectors
### Worksheet of Core Elements for Regional Hubs

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<th>Autism Training</th>
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|                |                |                                                      |   • Governor, Office of the                                              |
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|                |                |                                                      | • House of Representa-tives                                             |
|                |                |                                                      | • Human Rights Commission                                               |
|                |                |                                                      | • Institute for Public Policy, State                                    |
|                |                |                                                      | • Social and Health Services Department of County                        |
|                |                |                                                      | • Millage, Grants, etc.                                                 |

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Organizational Structure of Hubs to Local Region, State Coalition, Task Force

Autism Task Force
Original Members and Recommendations

WA Coalition, State & Local Agencies: Create a Plan

DOH, DSHS; DDD, MHD, DVR,

Local Coalition: Local Agencies & WA Coalition Reps: Local Planning

Local Regional Network

HUB: Tri-Cities
HUB: Yakima
HUB: Spokane
HUB: Seattle Tacoma
HUB: Vancouver
4 c) Autism Task Force Report from the Identification/Tracking/Services Subcommittee

September 19, 2007

Subcommittee Members

Geraldine Dawson, Ph.D. (Chair) Professor of Psychology, UW, Director, UW Autism Center
Nancy Simon, M.D. (Co-Chair) UW Physician, Parent Representative
Jane Campbell, Assistant Division Director, DCHA-DDD
Victoria T. Crescenzi, M.D. Pediatrician, Bremerton Naval Medical Center
Katie Hutchinson, PhD, MCH Assessment, WA State Dept. of Health
Felice Orlich, Ph.D. Clinical Assoc. Professor, UW, Director, UW Autism Center Tacoma
Kate Orville, MPH, Co-Director, Washington State Medical Home Leadership Network
Carolyn Taylor, MS, Autism Outreach Project Representative
Samuel Zinner, M.D., Asst. Professor of Pediatrics, UW

PRIORITY RECOMMENDATION #1 (IN-2) Ensure all individuals with ASD receive comprehensive health services

To ensure that all individuals with Autism and related conditions receive appropriate and accessible services within their communities, insurance coverage for evidenced base practices, including but not limited to, Early Intensive Behavioral Intervention (EIBI), is pivotal to increasing capacity, family resources and coordination across agencies. Within the state, precedence has been set by at least three major private insurers in the coverage of comprehensive services for children with Autism. Nationally, 19 states have successfully mandated insurance coverage that benefits children with Autism. The cost-benefit analysis in providing this coverage has been a major impetus in light of the substantive savings over an individual's life span. Currently within our state there exists a health disparity for families not enrolled with the four unique insurers. To remedy the lack of intervention services appropriate to children and youth with Autism and to create equity across the state, the priority recommendation #1 is to mandate insurance coverage for ASD services. Specifically, the recommendations are to:

- Extend insurance benefits to cover intervention for individuals with ASD (Autism Spectrum Disorder).
  - Consult with individuals from states such as South Carolina and Pennsylvania where successful legislation mandating state insurance coverage for ASD intervention was passed.
  - Specifically, mandate coverage of early intensive behavioral intervention (EIBI) and insurance certification of Board Certified Behavior Analysts (BCBA)

- Expand Medicaid benefits to increase capacity of Medicaid providers to provide equity in health care access.
  - Increase the number of psychological assessments (currently 1 per lifetime) allowed.
  - Increase rate of reimbursement to encourage more providers to accept Medicaid patients.
  - Provide benefits comparable to private insurance, including reimbursement for EIBI.
  - Certify applied behavior analysts (BCBA) and allow behavioral intervention to be provided by PhD level provider.
Support SB5750 Neurodevelopmental Therapy bill.
- Extend neurodevelopmental therapies (such as speech, occupational and physical therapy) to 18 years of age.
- Add certified behavioral analysts (BCBA) providers to this bill.

**PRIORITY RECOMMENDATION # 2 (TT-1 and TT-2) Screen all children in WA State for ASD before the age of 3 years, ideally by 18 months.** Screening, diagnosis, and referral to intervention for ASD and Asperger's Syndrome must take place across the lifespan.

Services for individuals with ASD and their families are lacking in large part because of a lack of adequate screening, diagnosis, and referral to existing services. There is a great need to increase awareness and expertise about ASD among providers. Specialty training in screening for autism is needed for service coordinators, Family Resources Coordinators (FRCs), and case managers. It is critical that providers also be knowledgeable about the full spectrum of ASD, including Asperger’s Syndrome and Pervasive Developmental Disorder, Not Otherwise Specified (PDD.NOS). Thus, the priority recommendation #2 is to provide training to insure that all children in WA State are screened for ASD before the age of 3 years, ideally by 18 months. Specifically, we recommend that the state:

- **Contract with First Signs** to develop a plan specific to Washington and provide state-wide training on use of screening tools (see www.firstsigns.org/) including:
  - Define and address the barriers to use of screening tools by physicians and other health care providers.
  - Develop an information and dissemination campaign.
  - Conduct regional trainings (including CMEs) (Continuing Medical Education credits).
  - Establish a dedicated resource page on First Signs Website.
  - Conduct an evaluation study
  - Estimated cost--$400,000 (See Appendix A).

In addition, the following recommendations are made:

- Establish a workgroup to develop a plan for:
  - Screening, diagnosis, referrals and issues related to ASD in adolescence and adulthood.
  - Identify training in use of screening tools to all primary referral sources including but not limited to, qualified health care providers, educators, service providers and case managers.
  - Identify existing resources and cost of implementation.

- Establish a workgroup to evaluate and make recommendations pertaining to availability and use of appropriate screening tools, referral, and services for individuals with Asperger's Syndrome and high-functioning autism, including identification of existing resources and cost of implementation.

- Ensure recognition by the Division of Developmental Disabilities (DDD) of Asperger's Syndrome as an eligible disability.
  - Provide training and support to DDD staff to assist higher functioning individuals with ASD.

- Ensure that children identified as possibly having an ASD are referred to services and qualified professional that provides evaluation of autism spectrum disorders and related conditions.
  - Refer to the Part C early intervention program (birth to three), or the local school district (over age three) for evaluation and, if eligible, appropriate services.
  - Simultaneously, refer children to the local regional network for information about qualified providers for diagnosis and other community based resources.
Collaborate with TRACE (Tracking, Referral, and Assessment Center for Excellence) whose mandate it is to identify and promote the use of evidence-based practices and models for improving child find, referral, early identification, and eligibility determination for infants, toddlers, and young children with disabilities. (See www.tracecenter.info).

**PRIORITY RECOMMENDATION # 3 (IN-3 and IN-4) Develop a work group to investigate and develop recommendations for timely identification, referral and tracking ensuring interagency coordination to avoid duplication of services across the lifespan.**

The goals of the work group will be to:

- Develop recommendations to improve the coordination and provision of care to facilitate timely referral and placement.
  - Develop strategies to build on and provide greater coordination among existing agencies that screen, diagnose, and provide services for children with ASD.

- Develop recommendations for creation of a state-level central registration process for autism and developmental disabilities, including timelines:
  - Explore existing Central Registries in Washington State and successful systems in other states to establish a state-level registration center:
    - Primary Referral Sources (PRS) would register the child or adult at the time of diagnosis of ASD.
    - PRS would also provide family with contact information about a local regional network.
    - PRS is defined as primary care providers, which include but are not limited to, early intervention providers, school districts and allied health providers.

- Develop a process for regional networks to establish dedicated local resource coordinators. The process should include but not be limited to, defining the following:
  - Minimum level of qualifications.
  - State and local training requirements.
  - Maximum caseload sizes to ensure that they can be responsive to the volume of newly diagnosed children and adults.
  - Regional guidelines for independent function.
  - Provision of unbiased, research-based information, referral, resources (local, state, and national) and linkages/coordination across regions.
  - Maintenance of state/local web-based information/referral system.
  - Explore existing local referral, information and outreach.
  - Establish a mechanism for referrals to Regional Network Resource Coordinators:
    - ASD Central Registry
    - Primary Referral Sources, with permission of the family/individual.
    - Families/individuals with ASD.
  - Establish mechanisms to ensure initial contact with families within 15 days of receipt of referral.

- Understand the methods and barriers to conducting autism and developmental disability surveillance and determine ways to address these barriers.
  - Consult with individuals from the Autism and Developmental Disabilities Monitoring Network (ADDMN) at both the national and state level.
➢ Review the ADDMN surveillance protocol (national standard for the surveillance of developmental disabilities) and determine which components within the current Birth Defects Surveillance System will facilitate autism and developmental disabilities surveillance.
➢ Develop recommendations for creation of a developmental disabilities surveillance system.

➢ Identify existing resources to support this system, identify gaps and establish a fiscal note.

➢ Timelines:
  Preliminary report by April 30, 2008.

PRIORITY RECOMMENDATION #4: (IN-2) Ensure all individuals with ASD receive comprehensive health services and coverage within a Medical Home.

➢ Provide training and back-up for physicians.
  ➢ Collaborate with Med Con, a consultation resource for primary care providers, to expand its consultative service to primary care providers who serve individuals with Autism.
    ▪ Provide training to consulting physicians.
    ▪ Promote use of Med Con across the region.
  ➢ Revise and expand the state medical home website to better address autism and related conditions. [http://www.medicalhome.org/diagnoses/autism.cfm](http://www.medicalhome.org/diagnoses/autism.cfm)
    ▪ Promote medical home website and resources.
    ▪ Use Child Health Notes (supported by the Department of Health CSHCN) to provide more information about autism to PCPs in WA. [http://www.medicalhome.org/leadership/chn_using_format.cfm#special](http://www.medicalhome.org/leadership/chn_using_format.cfm#special)
  ➢ Improve ARNP/PA(Physician Assistant)/medical school/residency training on ASD and related conditions
    ▪ Assess current training standards within Washington State programs
    ▪ Collaborate with training programs to increase awareness and surveillance of Autism and related conditions

➢ Improve access to high-quality medical home for individuals with ASD
  ➢ Explore successful programs nationally:
    ▪ Obtain consultation from the Waisman Center (They are leading a National Medical Home Autism Initiative.) [http://www.waisman.wisc.edu/nmhain/DESCRIPTION.HTML](http://www.waisman.wisc.edu/nmhain/DESCRIPTION.HTML)
  ➢ Explore regional successful medical home programs
    ▪ Armed forces as an example
  ➢ Make use of the Medical Home Leadership Network to increase high quality medical homes within the state to pilot learned strategies. [http://www.medicalhome.org/leadership/the_mhln.cfm](http://www.medicalhome.org/leadership/the_mhln.cfm)

Appendix A. Fiscal Information pertaining to Training in Screening for Autism

First signs ([www.firstsigns.org/](http://www.firstsigns.org/)) is a well-established organization that provide training on the use of autism screening tools. First Signs provides consultation and training based on an individual state or specific geographic region. First Signs has been highly successful in their approach and is well
established. An excellent example is the benefit to the state of Minnesota. Child Count data, collected in Minnesota a year after the implementation of the initial phase of the First Signs program, illustrates the effectiveness of the program: for those aged 0–21 years, the overall increase in identification of autism spectrum disorders was 23%; more notably, there was a 75% increase in the number of children in the 0–2 age group identified with autism spectrum disorders.

To establish a successful program, First Signs assesses:
- measurable goals and objectives
- size of target audience and geographic region
- infrastructure within the state or region
- budget
- barriers within a state to delivery
- ways to maximize available funding and existing resources

Based on the state and infrastructure assessment, a First Signs program may consist of:
- Educational mailings
- Press announcements, articles, and interviews with print and
- Broadcast press
- Television, print, and/or radio Public Service Announcements (PSAs)
- Training for healthcare providers, clinicians, and early childhood educators (offering CMEs) (Continuing Medical Education credits)
- Webcast training for those who are unable to attend a live training session
- Train-the-trainer workshops for Early Intervention professionals and others who wish to improve upon their community outreach to local healthcare providers
- First Signs screening kit for professionals who attend our trainings
- Parent brochures that contain important information about developmental screenings and a checklist of our healthy developmental milestones and ‘red flags’ for an immediate evaluation
- Links and resources specific to each state on the First Signs Web site at www.firstsigns.org
- Speaking engagements at selected pediatric conferences
- License to use our video, On the Spectrum: Children and Autism at conferences, seminars, or grand rounds within the state
- Research or evaluation studies

Based on Washington State demographics and potential training/dissemination needs, the following cost estimates were offered by First Signs:

**Option 1: $500,000**
Statewide press campaign
Television PSAs
115,000 parent brochures
6 regional trainings (including CMEs) + 3 train-the-trainer workshops + 12 mailings (6 training days spread out over a year)
30 Grand Rounds presentations
1000 screening kits tailored for Washington
Dedicated resource page on First Signs Website
Archived Webcast for 1 year
Dedicated Washington coordinator
Evaluation study (long and short term)

**Option 2: $380,000**
Statewide press campaign
Television PSAs
115,000 parent brochures
6 regional trainings (including CMEs) + 2 train-the-trainer workshops + 4 mailings (4 training days spread out any way)
1000 screening kits tailored for Washington dedicated resource page on *First Signs* Website
  Dedicated Washington coordinator
  Evaluation study (short term)

**Option 3: $280,000**
Statewide press campaign
Television PSAs
75,000 parent brochures
4 regional trainings (including CMEs) + 2 train-the-trainer workshops + 2 mailings (3 training days spread out any way)
700 screening kits tailored for Washington
  Dedicated resource page on *First Signs* Website
  Evaluation study (short term)

*Costs may be reduced by local coordination; evaluation coordinated through state universities and use of the train the trainer model. Given available Washington State existing resources, Option 2 is recommended by the ID/tracking subcommittee.*
Priority Recommendations and Implementation Plans

4 d) Autism Task Force Family-Centered Care Subcommittee Report

**Washington State Task Force Members**
Lauri Berreman, Local school district representative
Lou Colwell, OSPI
Geraldine Dawson, UW Autism Center
Monica Meyer, Education Service District
Felice Orlich, UW Autism Center (backup)
Marilyn Rasmussen, Washington State Senator
Pam Roach, Washington State Senator
Linda Rolfe, DSHS / Division of Developmental Disabilities
Ilene Schwartz, Expert in early intervention services
Dawn Sidell, Parent
Diana Stadden, Parent
Carolyn Taylor, Autism Outreach Project
Maureen Walsh, Washington State Representative
Brendan Williams, Washington State Representative

**Family Care Subcommittee Members**
Diana Stadden, co-chair
Dawn Sidell, co-chair
Crystal Blanco
Don Burbank
Leslie Carroll
Tracie Day-Hoppis
Angela Dawson
Sue Elliott
Debra Finck
Arzu Forough
Patty Gee
Alan Gill
Sally James
Erin Lynch
Carol L. Miller
Lance Morehouse
Cami Nelson
Felice Orlich
Helen Powell
Carolyn Taylor

**History**
In December of 2006 the Caring for Washington Individuals with Autism Task Force reported its recommendations to the Governor of Washington. A total of thirty-one recommendations were made in the areas of infrastructure, treatment, training and funding. There were six recommendations that were identified by the task force as essential first steps. Those six recommendations were:

1. Create regional autism centers of excellence in targeted areas of the state. (Regional Networks for Autism and Other Related Disorders)
2. Increase Washington’s capacity to identify and track people with ASD and the services they receive across their lifespan.
3. Screen all Washington children for ASD (Autism Spectrum Disorder) before the age of three years, ideally by 18 months.
4. Establish a minimum of one trained autism technical assistance specialist in each of the nine ESDs to provide support to teachers and staff.
5. Ensure that state agencies already required to provide services to people with ASD will have in place staff training on ASD and ASD supports.
6. Create autism services guidebook similar to the Ohio Services Guidelines for Individuals with ASD. The task force recommends that Washington’s guidebook include information and resources from birth through the lifespan.

Recommendations Considered Under Family-Centered Care

The Family-Centered Care Subcommittee identified the following recommendations as being essential first steps necessary for the improvement of systems for individuals with ASD. It was also decided by the members of the Autism Task Force that the family care component was intertwined in all the subcommittees.

Both TT-9 and F-8 pertain to the creation of an Autism Services Guidelines book for Washington State. This guidebook was identified as an essential first step in the recommendations from 2006 and the task force has been tasked in the 2007 proviso to compile information and draft the “Washington Services Guidelines for Individuals with Autism – Birth Through Lifespan” by June 30, 2008. Including the words “Services Guidelines” in the title has been confusing, causing people to think it is a resource guide of where to find services. The book is more than a guide to finding services. It will also provide information on the medical aspects of diagnostics and screening, identified best practices regarding evidence based interventions, identifying essential components of instruction for students with autism and related disorders, community transition tips, family involvement and other helpful information similar to the guidebook created in Ohio. The book should be available in print form and online. Creation of an autism license plate could help pay for the cost of creating and printing the book.

Although parents understand the usefulness of the guidebook, of more concern was having a physical person to connect to when a parent receives the diagnosis of autism for their child. The Regional Network Sub-committee is looking at this issue as part of each hub in the regional network. We strongly support the creation of a position or contract with an existing organization that already has such a position within each hub of the regional network that would be dedicated to answering calls and
emails from families looking for resources and information specific to autism as well as a listening ear from someone who understands. This position would generally be held by a knowledgeable parent of a child with autism.

TT-3 and TT-4 are of great concern to parents in this sub-committee as many families struggle to get the appropriate minimum number of hours of appropriate services for their child in the educational system. These recommendations are addressed more fully in the Education Sub-committee.

Although TT-10 (Increase the availability of child and adult care providers who are able to serve individuals with ASD, particularly individuals over age 12) was considered very important, it was not addressed as one of the three top priorities for the Family Care Subcommittee.

**Recommendations Identified as Priority**

- **TT-11:** Provide appropriate wrap around services for individuals with ASD and their families using ASD trained respite and personal care providers.
- **TT-12:** Provide family preservation services and strategies to help families of individuals with ASD stay together. (**TT-13:** When out-of-home placement is necessary, provide families with a variety of options that are age appropriate, offer ASD trained staff, and are in an environment designed to meet the needs of the individuals served.)
- **TT-9:** Develop an Autism Services Guidebook that can be used as a resource directory for parents, organizations, and providers who serve individuals with ASD and their families, birth through the lifespan.

**Planning Process**

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<td>1. TT-12: Provide family preservation services and strategies to help families of individuals with ASD stay together. (TT-13: When out-of-home placement is necessary, provide families with a variety of options that are age appropriate, offer ASD trained staff, and are in an environment designed to meet the needs of the individuals served.)</td>
<td>1. Look at DSHS partnership with schools on behavior training. 2. Support possible legislation for Intensive In-home Services through the HCBS waiver. This committee would suggest that a crisis team needs to be created that could be available to anyone needing immediate assistance. 3. Enhance phone support for families through resources such as the Autism Society of Washington help line, the University of Washington Autism Center help line, the NW Autism Center, the Autism Outreach Project and other organizations.</td>
<td>Linda Rolfe, Diana Stadden, Sue Elliott</td>
<td>Draft IBS legislation for the 2007 session has been created.</td>
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| 2. TT-11: Provide appropriate wrap around services for individuals with ASD and their families using ASD trained respite and personal care providers. | 1. Work with SEIU (Service Employees International Union) on training curriculum for providers. Suggest offering providers extra training around behavior issues for those willing to work with those with autism and other behavioral issues.  
2. Consider expanding the United Cerebral Palsy Respite program to be more inclusive of those with autism and to access funding for these supports.  
3. Look at Pope’s Kids Place. | Diana Stadden | |
| 3. TT-9 (F-8): Develop an Autism Guidebook that can be used as a resource directory for parents, organizations, and providers who serve individuals with ASD and their families, birth through the lifespan. | 1. Draft the guidebook, though change the name.  
2. Contact Ohio Autism Task Force to see how to use their guidebook as the basis for ours.  
3. Pursue legislation for creation of an autism license plate.  
4. Research Combating Autism Act for additional funding for the project. | Diana Stadden | Senator Rasmussen will pursue Senate Bill 5886 for an autism license plate. |

**Implementation Plan**

The Family-Centered Care Subcommittee has collaboratively worked on the above identified priority recommendations to formulate an implementation plan for immediate action. The committee’s intent was to isolate targeted recommendations that would have the most impact on families living with autism and other related disorders.

As discussed in the original Caring for Washington Individuals with Autism Task Force report from December 2006, “Families with children with ASD are particularly vulnerable to stress and are often isolated and lacking support.” “Supports that enable families to provide care for their loved ones with ASD in their own home and community are critical and provide many financial benefits for the state long term.”

Family Support America defines family support as “a set of beliefs and approaches to strengthening and empowering families and communities so that they can foster the optimal development of children, youth and adult family members.” “Family resilience is strengthened through culturally and linguistically effective family supports and social connection with other families who experience ASD.” The recommendations and implementation suggestions that will be outlined in the following sections reflect the Family Care Subcommittee’s desire to build upon and expand family’s abilities to best meet the unique and challenging needs of children on the autism spectrum.
Priority Recommendation #1: TT-12/TT-13

a) The first recommendation, identified by the Family-Centered Care Subcommittee as requiring immediate action, is providing family preservation services and strategies to help families of individuals with ASD stay together. When out-of-home placement is necessary, families need to be provided with a variety of options that are age appropriate, offer ASD trained staff, and are in an environment designed to meet the needs of the individuals served.

Currently there is a new trend of admitting children into institutions, a practice that our state had stopped years ago. These children are being placed out of home because of severe behavioral issues. Though not all have a diagnosis of autism, the behaviors are the common thread that families and school districts are finding themselves unable to address in a positive way.

DSHS is considering a partnership with schools to help train them in understanding behavior as communication as opposed to behaviors needing to just be controlled. This sub-committee would recommend that this type of training also be offered to families, possibly in a DVD format. The University of Washington Autism Center was provided with $65,000 in the 2007 legislative session to create a training DVD. We estimate the cost for a Behavior As Communication training DVD to be similar.

b) Advocates for those with developmental disabilities have drafted legislation for the 2008 session that addresses the need for intensive in-home services for families. This would be provided through Home and Community Based Service waivers. Intensive in-home services would be provided by a highly trained team of professionals. The team would help support the family and provide transition planning when they leave the program. They could deliver the services at home, in the school and in the community. An additional need is for a crisis team that could respond right away for any family needing immediate assistance. All crisis teams should coordinate with hospitals in the Regional Network for follow-up and diagnosis if needed.

c) There is a cost savings in connecting people to people. Peer networks have been shown by substantial research to reduce the total health-care cost of chronic diseases, by allowing emotional support and advice from others to improve the efficiency and effectiveness of care and behavior changes toward health. (See Appendix) In a parallel way, this committee believes that family-to-family care networks probably improve the efficiency of care provided, increase the speed at which families in crisis find help, reduce duplication of effort, and help sometimes prevent the tragic total breakdowns of families that result in children becoming wards of the state. Intact functioning families with access
to appropriate expert care save all Washington taxpayers money. Parent support to other parents is a vital part of the network that saves money. We need to spend more on parent-to-parent advice.

Currently the Autism Society of Washington, the University of Washington Autism Center, the Northwest Autism Center, the Autism Outreach Project, Parent to Parent and other organizations attempt to provide emotional support by phone to families and individuals needing someone to talk to that understands what they are going through. Enhancing the ability of those organizations currently offering this type of support to ensure families can connect with a “real person” is considered of high value to families and has been shown to be cost effective. They know that services may not be available because of funding shortfalls, but talking to someone who can listen and offer resources and suggestions of how to address various issues can be the support that gets them through that day. Once the guidebook is created it should be linked to these “real persons”.

**Priority Recommendation #2: TT-11**

The second recommendation identified by the Family-Centered Care Subcommittee as requiring immediate action is that Washington State must create a coordinated statewide training program to provide consistent, standardized and culturally effective training on ASD for Medicaid Personal Care and respite providers. We need to identify training opportunities that currently exist within the state of Washington in an effort to not duplicate opportunities but to work collaboratively with entities such as University of Washington, the Autism Outreach Project and other agencies or organizations to create coordinated training opportunities that in particular address behavior as communication.

The Long Term Care Task Force for Washington State is currently looking at training requirements for providers. The Autism Task Force needs to collaborate with the Long Term Care Task Force as they develop the curriculum, as well as whoever is identified to do the training to ensure that appropriate training is made available to providers and is required in order to work with children or adults with individuals with behavioral disorders. The University of Washington received funding in 2007 to create a training DVD for parents and professionals, but training specific to personal care and respite providers for addressing and reducing behavioral issues is also needed. The support a parent gives their child in caregiving is different than a contracted caregiver would provide because the parent knows their child so well having provided continuous care throughout their life.

Currently United Cerebral Palsy runs a small program called Respitality that provides weekend getaways to parents of children with disabilities. UCP solicits companies for donations of hotels, restaurants and other fun activities and provides them to the parents free of charge in order to give
them a break. Respite is reimbursed, but families have to find their own provider. There is a long waiting list for this program. It would be good to expand the idea to work for families of children with autism and behavior disorders. Another program in Lewis County called Pope’s Kids Place provides respite for a weekend away.

**Priority Recommendation #3: TT-9 and F-8**

The third recommendation that the Family-Centered Care Subcommittee has identified as a priority is the creation of the “Washington Services Guidelines for Individuals with Autism – Birth Through Lifespan”. This has already been identified in the 2007 proviso as one of the priorities for this task force. Ohio created a similar book that only addresses birth through 21. Legislators acknowledged that the book for Washington State must address adult issues also.

We will need to contact the Developmental Disabilities Council in Ohio to find out the procedure to use the basic content of their book rather than recreating it. Some of the content will need to be updated and modified to be appropriate for our state as well to add adult issues.

Including the words “Services Guidelines” in the title has been confusing, causing people to think it is a resource guide of where to find services. That is not the intent. The book should also provide information on the medical aspects of diagnostics and screening, identified best practices regarding evidence based interventions, identifying essential components of instruction for students with autism and related disorders, community transition tips, family involvement and other helpful information similar to the guidebook created in Ohio. A more appropriate title would be “Essential Components for Washington State Individuals with Autism – Birth Through the Lifespan”.

In the 2007 legislative session Senate Bill 5886 was introduced to create an autism license plate. The Autism Society of Washington was designated as the statewide non-profit organization that the funding would flow through. The bill did not pass because of a moratorium on specialty plates which has now been lifted. There is a cost to set up the license plate which is paid off through the sale of the plates. Once the plate has reached enough sales, which takes one to two years, an account would hold the money and would help with the cost of printing the book once the Autism Task Force had finished creating it.

Another source of funding for the printing and distribution of the books is through funding from the federal Combating Autism Act. The Act authorizes activities to increase public awareness of autism. More research needs to be done to learn how to access these funds.
Summary

- The Autism Task Force Family-Centered Care Subcommittee is requesting the legislature support the creation of specialized training regarding behavioral issues in children with autism for parents and school staff that promotes understanding of behaviors as communication.

- The Autism Task Force Family-Centered Care Subcommittee is requesting the legislature adopt an Intensive In-home Services bill that would allow families to receive in-home supports, thereby reducing and eliminating the trend of institutionalizing children.

- The Autism Task Force Family-Centered Care Subcommittee is requesting that the Long Term Care Task Force consider specialized training for providers working with individuals with autism and other behavioral disorders.

- The Autism Task Force Family-Centered Care Subcommittee will continue work on the creation of a guidebook with the title to be changed to “Essential Components for Washington State Individuals with Autism – Birth Through the Lifespan”. We request that the legislature pass SB 5886 so that the process can be put in place to begin collecting funds from the general public from an autism specialty license plate.

Appendix

The Autism Society of Washington (ASW) has been supporting families in Washington State since 1973. ASW is a volunteer organization that has had phone support since its inception. ASW currently funds one paid position that is dedicated to answering phone calls for 10 hours per week. This person volunteers time above that as more calls come in than paid time allows. Some board members and local chapter leaders for the organization also assist with returning phone calls. The ASW staff position is currently paid $10.00 an hour with no benefits. This position is typically held by a parent of a child with autism. ASW has multiple contacts with many of the families and adults with ASD seeking our help. After initial phone contact with ASW, which can last anywhere from 15 minutes to two hours, families are referred to a local chapter contact where they are also provided with support from volunteers in that area. ASW continues to receive return calls from families as they seek more resources and information. Calls involve challenges around diagnosis, assessment, education, healthcare, respite care and difficulties accessing services, especially for adults, in their area. ASW also refers families to its online listserv which provides information and resources as well as local chapter meeting and support group information to help families stay connected to each other.

The University of Washington currently funds one full time position for answering phone calls from families. That position is paid around $35-40K annual salary with 28% benefits. Calls involve
challenges around diagnosis, assessment, education, healthcare and difficulties accessing services in their area. Calls are also referred on to parent organizations in the caller’s area.

The Autism Outreach Project (AOP) is a State Needs Project funded by OSPI (Office of the Superintendent of Public Instruction) and ITEIP (Infant Toddler Early Intervention Program) and the age group it covers is from birth to 21 years old. AOP has a part time Family Specialist who has received extensive professional training about autism spectrum disorders and also is a parent of a child with an autism spectrum disorder.

The Family Specialist position is budgeted at 17 hours per week. The range of services provided to families includes: information and referrals, resources, support, providing information about diagnostic centers, support groups, lending library materials (over 1000 items), autism education, mailing out autism training materials, and answering questions by phone or email. The average phone call ranges from 30 to 60 minutes. There is more capacity to increase this position to full time status with increased revenue. Last year there were 1,352 phone calls to AOP specifically on autism (90% of calls made to the project are from parents or family members). The annual cost for the Autism Outreach Project Family Specialist would be $28,000 for 32 hours per week (includes salary and benefits). The total cost is $42,000 to increase to 40 hours per week (includes salary and benefits).

The Northwest Autism Center (NAC) in Spokane, Washington has been providing phone and email support to individuals with autism spectrum disorders and their families since its formation as a nonprofit organization in November of 2004. During the first eight months of 2007, they have responded to just over 850 autism-related calls and emails from parents, educators and providers, or an average of 108 contacts per month. 91% of these contacts originate from residents of the greater Spokane area and 40 mile radius, which includes a number of small towns with few resources or services; 7% are from areas of Eastern Washington but outside our designated service area; and 2% from beyond Eastern Washington. Out of these 850 contacts, only about 30 are from individual adults on the spectrum. Approximately 90% are from parents, grandparents or guardians of children with ASD. The remaining 10% are from providers seeking help on behalf of students, patients and clients and their families. Of the family contacts, over half are referred to NAC by schools, healthcare providers and service agencies in the region.

Initial phone interviews with parents/guardians of children on the autism spectrum require a minimum of 15 minutes, with the average first call ranging from 30 to 60 minutes; 80% of these initial contacts result in follow-up emails or mailings. NAC has multiple contacts (average of two or three contacts per
family) with over 2/3 of families seeking help. Over 80% of calls involve challenges around diagnosis, assessment, education, healthcare, and difficulties accessing and/or coordinating services in the region.

The family support staff person for NAC is an educator and parent of a child with autism. Her position is budgeted for 12 hours per week and currently she offers an additional 5-7 volunteer hours per week, simply to meet demand. Simple requests for referral information are handled by the NAC receptionist.

Washington State Parent to Parent Preliminary numbers for last year show over 10,000 calls from parents or family members of all developmental disabilities for help across the state. Some families called more than once, especially in times of stress. Between one quarter and one third of those calls were from families of children with autism and related disorders. If you estimate that about 1/3 of the calls are families of kids on the autism spectrum, there are about 4,000 families currently on their mailing list who have a child with autism spectrum disorder. Many new families are added every day.

Greg Schell, Director of the Washington State Fathers Network, shared that the Washington State Fathers Network serves about 450 families who have kids "on the spectrum"—about 25% of the total number of families they serve, a very conservative estimate.
4 e) Autism Task Force Education Subcommittee Report

Washington State Task Force Members
Lauri Berreman, Local school district representative
Lou Colwell, OSPI
Geraldine Dawson, UW Autism Center
Monica Meyer, Education Service District
Felice Orlich, UW Autism Center (backup)
Marilyn Rasmussen, Washington State Senator
Pam Roach, Washington State Senator
Linda Rolfe, DSHS / Division of Developmental Disabilities
Ilene Schwartz, Expert in early intervention services
Dawn Sidell, Parent
Diana Stadden, Parent
Carolyn Taylor, Autism Outreach Project
Maureen Walsh, Washington State Representative
Brendan Williams, Washington State Representative

Education Subcommittee Members
Lauri Berreman, co-chair
Carolyn Taylor, co-chair
Lou Colwell
Ilene Schwartz
Monica Meyer
Linda Rolfe
Carol Miller
Milani Smith
Shelley Marquette
Val Lynch
Monique Bartoldus
Maryann Barnes
Gretchen Mertes
Linda Hawkins
Nancy Rosenburg
Arzu Forough
Ronda Schelvan

History
In December of 2006 the Caring for Washington Individuals with Autism Task Force reported its recommendations to the Governor of Washington. A total of thirty-one recommendations were made in the areas of infrastructure, treatment, training and funding. There were six recommendations that were identified by the task force as essential first steps. Those six recommendations were:

1. Create regional autism centers of excellence in targeted areas of the state. (Regional Networks for Autism and Other Related Disorders)
2. Increase Washington’s capacity to identify and track people with ASD (Autism Spectrum Disorder) and the services they receive across their lifespan.
3. Screen all Washington children for ASD before the age of three years, ideally by 18 months.
4. Establish a minimum of one trained autism technical assistance specialist in each of the nine ESDs (Educational Service Districts) to provide support to teachers and staff.
5. Ensure that state agencies already required to provide services to people with ASD will have in place staff training on ASD and ASD supports.

6. Create autism services guidebook similar to the Ohio Services Guidelines for Individuals with ASD. The task force recommends that Washington’s guidebook include information and resources from birth through the lifespan.

**Recommendations Identified as Priority**

The Education and Training Subcommittee identified the following recommendations as being essential first steps necessary for the improvement of systems for individuals with ASD. TT-5 and TG-1 directly align with the original six recommendations that were identified by the task force as items requiring immediate action in the December 2006 report.

- TT-5 Establish a minimum of one trained autism technical assistance specialist in each of the nine Education Service Districts to provide support to teachers and staff.
- TG-1 Washington State must create a coordinated statewide training program to provide consistent, standardized and culturally effective training on ASD for individuals, families, educators, health care and all service providers.
- TT-3 All Washington State children, birth to five years of age, diagnosed with ASD, or for whom ASD is suspected, must have access to a minimum of 25 hours a week of appropriate educational services.

**Planning Process**

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<th>Recommendation</th>
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<tr>
<td>1. TT-5 Establish a minimum of one trained autism technical assistance specialist in each of the nine Education Service Districts to provide support to teachers and staff.</td>
<td>2. Fiscal Note 3. Job Description i. Days / year ii. Responsibilities</td>
<td>Carol, Val, Monica, Gretchen, Lauri, Shelley</td>
<td>Will be rolled into job description for ESD Autism position</td>
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<td>2. TG-1 Washington State must create a coordinated statewide training program to provide consistent, standardized and culturally effective training on ASD for individuals, families, educators, health care and all service providers.</td>
<td>4. Identify training targets. 5. Identify what training opportunities currently exist within the state. 6. Collaborate with AOP on training efforts. 7. Link to above recommendation.</td>
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<td>3. TT-3 All Washington State children, birth to five years of age, diagnosed with ASD, or for whom ASD is suspected, must have access to a minimum of 25 hours a week of interventions</td>
<td>1. Identify “seeds of excellence” within Washington State. These would be school districts that are currently implementing the gold standard of 25 hours per week at the preschool. Recommendation is that committee continue to investigate. Schedule face to face meeting for early October to tackle language, definitions etc. In linking with action item #1,</td>
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Implementation Plan

The Education Subcommittee has collaboratively worked on the above identified priority recommendations to formulate an implementation plan for immediate action. The committee’s intent was to isolate targeted recommendations that would have the most impact on students with autism and other related disorders and the educators and professionals that serve them. As discussed in the original Caring for Washington Individuals with Autism Task Force report from December 2006, “Lack of ASD trained teachers and mentors in the school district creates great difficulty in implementing ASD programs and strategies…Best practices and successful strategies must be shared and made more widely understood; it is possible to develop and implement appropriate educational services and supports for each individual with ASD, through training of staff and utilization of already existing knowledge and best practices.” The recommendations and implementation suggestions that will be outlined in the following sections reflect the Education Subcommittees desire to build upon and expand educator’s abilities to best meet the unique and challenging needs of children on the autism spectrum.

Priority Recommendation #1: TT-5

The first recommendation, identified by both the Autism Task Force and the Education Subcommittee as requiring immediate action, is establishing a minimum of one trained autism technical assistance specialist in each of the nine ESDs to provide support to teachers and staff. The implementation of this recommendation has the ability to build capacity within regions and school districts that previously, due to geography or lack of trained individuals, lacked expertise in the field of autism and educational strategies and supports. “A technical assistance person in each education service district is critical to the success of educators and other professionals in providing positive, research based programs and supports with the schools” (Caring for Washington Individuals with Autism Task Force report from December 2006).

This recommendation was implemented in ESD 105 (Yakima) in 2006 with creative funding and has been active in ESD 112 on a volunteer basis. ESD 105 has an Autism Education Coordinator (AEC) who provides training to educators on autism spectrum disorder and education strategies, provides consultation to school districts on specific students, serves as a liaison between Children’s Village (the
Caring for Washington Individuals with Autism Task Force

birth to three agency) and school districts and provides other services as requested. Over 700 educators and professionals received some level of autism specific training during the 2006-2007 school year. The position has proven to be very successful and is strongly supported by school districts but funding is a constant concern. ESD 112 has established a Regional Autism Consulting Cadre. The ESD 112 Regional Autism Consulting Cadre is a group of concerned, interested professional educators and parents seeking to enhance their base of knowledge regarding persons with Autism. Further, the cadre works to develop and support the dissemination of best practice information through meaningful consultation to and collaboration with school districts in the ESD 112 region. The Cadre works with school districts to provide consultation services to assist in the development of appropriate programs for students with autism, certain types of assessments including FBAs (Functional Behavioral Assessments), training activities for staff and parents, resources for staff and parents and legally defensible IEPs (Individual Education Plans).

The Education Subcommittee has drafted job functions and responsibilities which can be viewed in Appendix A. It is the desire of the Autism Task Force and Education Subcommittee that these functions are taken into consideration by each of the nine ESDs as they develop a region specific job description. A fiscal note has also been drafted to request legislative funding for the position. It is the recommendation of the committee that the legislation fund, at a minimum, one Autism Education Network Coordinator (AENC) in each ESD and a .5 administrative assistant for each AENC (see Appendix B).

Priority Recommendation #2: TG-1
The second recommendation identified by the Education Subcommittee as requiring immediate action is that Washington State must create a coordinated statewide training program to provide consistent, standardized and culturally effective training on ASD for individuals, families, educators, health care and all service providers. It is the recommendation of the subcommittee that portions of the language from TG-1 be directly linked to the above discussed ESD Autism Education Coordinator position. The subcommittee envisions that one of the components of the AENC position will be to create and implement coordinated statewide trainings specific to educators and education strategies. An additional component of the AENC position will also be to identify training opportunities that currently exist within the state of Washington in an effort to not duplicate opportunities but to work collaboratively with entities such as University of Washington, the Autism Outreach Project and the IECC (Infant and Early Childhood Conference) to create coordinated training opportunities that speak to the unique disciplines and areas of specialty within education.
It is anticipated that the ESD Autism Education Network Coordinators will meet on a consistent basis to identify statewide training needs and current gaps, develop training modules to address identified gaps and present trainings within each ESD. As previously mentioned, ongoing collaboration with other entities such as the Autism Outreach Project will be critical in determining areas of focus. The Autism Outreach Project currently surveys school districts on an annual basis for data tracking purposes and to also identify training needs. It will be critical that data is analyzed not only through a statewide lens but also taking into account how needs may differ regionally dependent on base knowledge, cultural implications, language barriers etc.

**Priority Recommendation #3: TT-3**

The third recommendation that the Education Subcommittee has identified as a priority is that all Washington State children, birth to five years of age, diagnosed with ASD, or for whom ASD is suspected, must have access to a minimum of 25 hours a week of appropriate educational services. The committee had discussion at length surrounding the language, potential interpretations and definitions encompassed within this recommendation. The committee would propose additional conversation surrounding the wording of the recommendation. Future conversation may visit revisions to reflect the following: All Washington State children, birth to five year of age, diagnosed with ASD, or for whom ASD is suspected, must have access to a minimum of 25 hours a week of interventions. It is the current belief of the committee that this terminology better reflects the menu of services that could be utilized to comprise the 25 hours (i.e. classroom instructional opportunities, inclusive playgroups, home visits, speech and OT services, family support and training etc). The committee strongly cautions that services always take into consideration developmental appropriateness. “Appropriate services for a six month old child will be very different from what is appropriate for an 18 month old. Appropriate services for the very young child may include but not be limited to: family support, family coaching, education, and other services.” (Caring for Washington Individuals with Autism Task Force report from December 2006).

The Education Subcommittee recognizes that this identified recommendation requires additional research and consideration prior to implementation. It is the recommendation that additional time be allotted for the Education Subcommittee to investigate the following:

- Identify “seeds of excellence” within Washington State. These would be school districts that are currently implementing the gold standard of 25 hours per week. This would include surveying those identified school districts to:
  - Identify what populations are served in the program
Caring for Washington Individuals with Autism Task Force

- Identify the ages currently served in the program
- Identify funding sources for the program
- Identify the staff to student ratio within the program
- Identify methodologies utilized within the program
- Identify unmet needs or gaps within program as perceived by the school district

- Define the term *suspected* within the recommendation.
- Define the term *interventions* versus *educational services*.
- Provide case study scenarios of service delivery options demonstrating how 25 hours of intervention would vary across age, the spectrum of autism and developmental level.

**Summary**

- The Autism Task Force Education Subcommittee is requesting immediate funding from the legislature to support the implementation of the Autism Education Network Coordinator (AENC) in each the nine Education Service Districts within the state of Washington.
  - The total fiscal request is $1,800,000.
- The Autism Task Force (ATF) Education Subcommittee proposes that one responsibility / function of this proposed AENC position would be to work with existing training providers to create a coordinated statewide training program. It will be essential that all nine ESD AENCs collaborate on a consistent basis to ensure that the trainings are reflective of regional needs and demographics.
- The ATF Education Subcommittee is recommending the subcommittee continue to meet to further research and investigate TT-3, the 25 hour provision for birth to five. It is the opinion of the subcommittee that this is a recommendation that is of priority but warrants substantial discussion and conversation.

**Appendix A. Autism Education Network Coordinator**

**Job Functions and Responsibilities**

- Provide ongoing leadership, expertise, training and consultative services to school districts, birth to three agencies, early intervention agencies and other identified entities that support or necessitate the usage, identification and implementation of research based practices.
- Develop infrastructure to facilitate increasing school districts, birth to three agencies, early intervention agencies and other identified entities capacity to serve children birth – 21 with ASD and other related disorders.
- Collaborate with other eight ESD Autism Education Network Coordinators to identify statewide training needs and current gaps, develop training modules to address identified gaps and present trainings within each ESD. This will include ongoing collaboration with U of W, the Autism Outreach Project, the IECC and other training providers to avoid duplication of offerings.
Priority Recommendations and Implementation Plans

- Participate in local efforts to gather demographic data regarding children with autism. Report data gathered to the Caring for Individuals with Autism Task Force Identification and Data Committee and the OSPI (Office of the Superintendent of Public Instruction) Autism Outreach Project.
- Continue to remain current in autism strategies, causation, incidence and prevalence, curriculums, methodologies, legal references and implications surrounding educational service and supports for students with autism and other related disorders.
- Conform to the principles, values and mission of each ESD.

Appendix B. Autism Education Network Coordinator

Fiscal Summary

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4 f) **Steering Committee Legislative Information**

**Steering Committee Legislative Packet References**


   [http://archpedi/ama-assn.org/cgi/content/full/161/4/343](http://archpedi/ama-assn.org/cgi/content/full/161/4/343)

   [http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5601a1.htm](http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5601a1.htm)

### Table: Task Force and Legislation by State

<table>
<thead>
<tr>
<th>State</th>
<th>Legislation</th>
<th>Task Force</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alaska</td>
<td>Dec. 2006</td>
<td>GCDSE Ad Hoc Committee</td>
<td>Although incremental changes have occurred on behalf of children and adults with Autistic Spectrum Disorders (ASD) in Alaska, the pace and amount of change has been inadequate to meet needs. Alaska GCDSE (Governor’s Council on Disabilities and Special Education) Ad Hoc Committee on Autism reports findings and recommendations. <a href="http://www.hss.state.ak.us/Gcdse/Publications/pdf/2006_autism.pdf">Link</a></td>
</tr>
<tr>
<td>Arizona</td>
<td>June 2006</td>
<td>Recommendations</td>
<td>The Arizona Legislature and Governor Janet Napolitano recently approved two separate measures bringing a total of $9.6 million to autism research and support services. One measure, Arizona Senate Bill 1355 appropriated $7.1 million to fund autism research at the Translational Genomics Research Institute. TGEN is part of an ongoing joint research collaboration between TGen and the Southwest Autism Research &amp; Resource Center, or SARRC. The money will help fund research aimed at producing an early diagnostic test to identify children at-risk for autism and, moreover, what type of autism an at-risk child might eventually develop. The state-appropriated funds are a launching point for securing future funding for a proposed $50 million Arizona Autism Research Initiative designed to not only improve early detection and subclassification, but also provide new medicines for autism based on a firm understanding of who will get it, what form an affected individual has, and what causes it. “Arizona has decided to focus on this area as a way to make the biggest impact against the disorder in the shortest amount of time, based upon our area of competence. Not only is this a unique opportunity that will benefit those locally and statewide, but nationally as well,” said Dr. Jeffrey Trent, TGen president and scientific director. <a href="http://www.autismspeaks.org/government_affairs/arizona_legislation.php">Link</a></td>
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<tr>
<td>State</td>
<td>Legislation</td>
<td>Task Force</td>
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| California   | 1997        | Reconvening             | LEGISLATIVE BLUE RIBBON COMMISSION ON AUTISM  
Task Force on Education and Professional Development  
CDC is now funding Centers of Excellence for Autism and Developmental Disabilities Research and Epidemiology (CADDRE) in California, Colorado, Maryland/Delaware, and Pennsylvania. For information:  
[http://www.cdc.gov/ncbddd/dd/ddautism.htm](http://www.cdc.gov/ncbddd/dd/ddautism.htm)  
**Combined Centers Study**  
The California center will work with the other CADDRE programs to find causes of ASDs or factors that make it more likely that a child will have an ASD. Families who take part in the study will answer survey questions, children with ASDs will be tested, and staff will look at medical records from when the children were born. Children ages 3-5 years will be included in the Combined Centers Study.  
**Special Studies**  
The California center is particularly interested in identifying biomarkers for early identification of children with autism. The first project will be a study focusing on biomarkers in newborn blood specimens from children who are later diagnosed with autism. We will also gather information to help us understand how autism is experienced in culturally specific communities.  
**Sharing Information**  
The California center will share what is learned from these studies through mailings to ASD support groups and families, the media, and professional organizations. Information will also be shared through conferences, scientific publications, and the center’s Web site.  
and more.... |
| Colorado     | April 2006  | Executive Summary       | Colorado Autism Task Force has adopted an operational definition of autism for the purpose of creating guiding principles for serving children with autism. The word autism is used in this manual to refer to the broader spectrum of autism.  
Jane Amundson et al  
[Colorado Manual for Working with Children with Autism Spectrum Disorders](http://cde.state.co.us/cdesped/download/pdf/WkgChldrnAutism.pdf)  
**Connecticut**  
1993, 1997  
Recommendations  
SERC (State Education Resource Center) The Focus on Autism Initiative was created as a response to findings of the Connecticut Task Force on Issues Relating to the Education of Children with Autism.  
[www.ctserc.org/initiatives/autism](http://www.ctserc.org/initiatives/autism)  
**Delaware**  
May 2007  
Recommendations  
House Resolution 89 created a task force to review service needs for adults on the autism spectrum who are not currently supported by any adult agency. The Speaker of the House appointed LDAF member Angie Sipple to serve on the Task Force. More information on the task force is available through the Delaware legislature’s web site  
[http://www.ldaf.com/advocacy.html#General_Assembly_Adult_Autism_Task_Force](http://www.ldaf.com/advocacy.html#General_Assembly_Adult_Autism_Task_Force) |
<table>
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<tr>
<th>State</th>
<th>Legislation</th>
<th>Task Force</th>
<th>Action</th>
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</thead>
<tbody>
<tr>
<td>Illinois</td>
<td>Sept 2005</td>
<td>Recommendations</td>
<td>The Autism Task Force convenes family members, service providers, educators, legislators, departmental staff, and researchers to study and assess the needs of people with Autism and Autism Spectrum Disorders across the lifespan. <a href="http://www.dhs.state.il.us/projectsInitiatives/theautismtaskforce/ASD-report-2006.pdf">Link</a></td>
</tr>
<tr>
<td>Indiana</td>
<td>Mar 2006</td>
<td>Recommendations</td>
<td>The Indiana Department of Education’s Division of Exceptional Learners Task Force on Autism Spectrum Disorders invites you to visit our website at <a href="http://doe.state.in.us/exceptional/asdtaskforce">Link</a>. This website describes the originating purpose for the Task Force, members, and the guiding principles. In addition, you will be able to review the meeting notes, recommendations and informational products. Please visit the site regularly to get updated information. <a href="http://www.handsinautism.org/taskforceann.html">Link</a></td>
</tr>
<tr>
<td>Kansas</td>
<td>May 2007</td>
<td>Naming Task Force Members</td>
<td>The Kansas Autism Task Force was created by SB 138, which was signed into law by Governor Sebelius on May 11, 2007. The task force will make recommendations to the Legislative Educational Planning Committee regarding potential legislation to improve the availability or accessibility of services for the screening, diagnosis and treatment of children with autism, as well as programs to assist their parents. <a href="http://www.governor.ks.gov/news/NewsRelease/2007/nr-200705110b.htm">Link</a></td>
</tr>
<tr>
<td>Mississippi</td>
<td>July 2007</td>
<td>Naming Task Force Members</td>
<td>July 6, 2007 GOVERNOR BARBOUR APPOINTS SULLIVAN TO AUTISM TASK FORCE (Jackson, Mississippi)—Governor Haley Barbour has announced the appointment of Elle Sullivan, of Taylorsville, to the newly-created Caring for Mississippi Individuals with Autism Task Force, which will study ways to improve identification and treatment of Autism Spectrum Disorders (ASD). <a href="http://www.governorbarbour.com/appointments/2007/jul/apptSullivanE.htm">Link</a></td>
</tr>
<tr>
<td>Nevada</td>
<td>June 2007</td>
<td>Members to be announced</td>
<td>Autism Task Force Legislation – 2007 Members to be announced <a href="http://www.leg.state.nv.us/74th/Interim/NonLeg/Autism/">Link</a></td>
</tr>
<tr>
<td>New Hampshire</td>
<td>Nov 2001</td>
<td>Recommendations</td>
<td>In November 2001 the New Hampshire Division of Developmental Services brought together family members, private providers, and representatives from State and local agencies to form the New Hampshire Task Force on Autism. Over the next year and a half the Task Force, working in five subcommittees, examined issues affecting the care, treatment, and quality of life of individuals with autism spectrum disorder (ASD). The work of the subcommittees on Etiology and Diagnosis of ASD and on Interventions and Treatment Approaches is presented here. The work of the three other</td>
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### Caring for Washington Individuals with Autism Task Force

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<thead>
<tr>
<th>State</th>
<th>Legislation</th>
<th>Task Force</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nevada</td>
<td></td>
<td></td>
<td>subcommittees – the Role of Publicly Funded Agencies, Accessibility and Inclusion, and Statewide Capacity Building – is documented in the New Hampshire Autism Task Force Report Part Two. Members of the Task Force put in hundreds of hours, much of it donated. Without their sustained commitment this report could not have been completed. For this commitment and for the depth of experience, skill, and wisdom that the members brought to their work a sincere appreciation is extended. <a href="http://www.autism-society-nh.org/atf.pdf">http://www.autism-society-nh.org/atf.pdf</a></td>
</tr>
<tr>
<td>Ohio</td>
<td>June 2003</td>
<td>Recommendations</td>
<td>Ohio Autism Task Force OAT On June 26, 2003 Governor Taft signed into law House Bill 95, biennial budget legislation. Included within the budget bill were provisions providing for the creation of the Ohio Autism Taskforce (OAT). The bill required the OAT to investigate the increasing incidence of autism in Ohio and to determine what, if any, gaps exist in the delivery of services to individuals with autism in Ohio. The OAT was charged with presenting a set of recommendations based upon its findings to the Governor, Speaker of the House, and President of the Senate. The OAT consisted of twenty-two members, eighteen members appointed by the Governor and four members of the Ohio General Assembly. The Governor’s appointments included an individual with autism, parents of individuals with autism, providers, educators, pediatricians, members of the Governor’s cabinet and others interested in and connected to the issue of autism. <a href="http://www.asgc.org/Ohio_Autism_Taskforce.htm">http://www.asgc.org/Ohio_Autism_Taskforce.htm</a></td>
</tr>
<tr>
<td>Oregon</td>
<td>1988</td>
<td>Recommendations</td>
<td>Oregon Technical Assistance Corporation Initiative for Autism Project; Autism Supports Autism supports teach families, caregivers and educators a variety of positive, structured, visual support strategies that help people with autism and related disorders understand their environment and become more independent in daily life. OTAC’s Autism Supports program concentrates on some of the essential ingredients of a self-directed life: knowledge, skills, independence and community connections. Our person centered approach boosts self-esteem and confidence. Our training and technical assistance emphasize proactive strategies that are tailored to the unique needs and strengths of the person with autism. The strategies we use help people with autism to understand their environment, become more independent in daily life and have positive experiences in the home and community. Our work is based on the principles of Structured Teaching, developed by the University of North Carolina TEACCH (Treatment and Education of Autistic and related Communication handicapped CHildren) Division and Positive Behavior Support strategies. OTAC staff is available to develop workshops that provide awareness and knowledge levels of information. We provide &quot;hands-on trainings that involve people with autism as co-trainers. Our</td>
</tr>
<tr>
<td>State</td>
<td>Legislation</td>
<td>Task Force</td>
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</table>
| Pennsylvania| 2004        | Recommendations   | Final Report  
December 2004  
Office of the Secretary  
Room 333, Health and Welfare Building  
PO Box 2675  
Harrisburg, Pennsylvania 17105  
http://www.dpw.state.pa.us/General/AboutDPW/SecretaryPublicWelfare/AutismTaskForce/  
Bureau of Autism Services Initiatives  
2004 Autism Task Force Report  
Estelle B. Richman, Secretary of Public Welfare for the Commonwealth of Pennsylvania, established the Autism Task Force in the summer of 2003 to develop recommendations that will improve the organization, financing and delivery of services and treatment.  
About the Bureau of Autism Services  
Autism Services Initiatives 2006-07  
Information about Nina Wall-Cote  
Information about the director of the Bureau of Autism Services.  
http://www.dpw.state.pa.us/Disable/AutismServices/AutismInitiatives/ |
| Texas       | Nov 2005    | Texas Council on Autism and Pervasive Developmental Disorder | TEXAS COUNCIL ON AUTISM AND PERVASIVE DEVELOPMENTAL DISORDERS  
Adopted November 18, 2005  
http://www.dads.state.tx.us/autism/Bylaws.pdf |
The Mission of the Vermont Autism Task Force is to coordinate the efforts of interested parties who serve individuals with autism spectrum disorders and their families, and to promote the implementation of best practices throughout the state of Vermont. 2006-2007
http://www.autismtaskforce.com/about.html

Virginia Early Intervention Autism Initiative
http://www.infantvap.org/documents/wkg-AUTISMMeeeting12182002.pdf

Governor James Doyle of Wisconsin this week said he believes insurance companies should cover autism services for children. Doyle, a Democrat, said he would support legislation filed April 23 by Senate Majority Leader Judy Robson "which would require group insurance policies to provide treatment and care for children with autism spectrum disorders."

The governor's brief statement urges Wisconsin lawmakers to withstand the expected opposition of the health insurance industry: "This proposal will help provide the care and support that children across our state living with autism need and deserve. I hope the Legislature will work in a bipartisan way and side with the children and families living with this disease, and not with the big insurance companies."

Arzu Forough, Autism Speaks Legislative Advocacy Chair-Washington State
Appendix 5

Task Force Recommendations

Caring for Washington Individuals with Autism

Task Force Recommendations in Brief

December 2006

INFRASTRUCTURE (IN)
IN-1
Create and enhance Regional Autism Centers of Excellence in targeted areas of the state to provide diagnostic services, therapies, and training for parents and professionals; coordinate services currently available; and address gaps in services.
IN-2
Ensure all individuals with ASD receive comprehensive health services and coverage within a Medical Home.
IN-3
Contact will be initiated for persons with ASD by a service provider within 15 days of receiving a diagnosis.
IN-4
Increase Washington State’s capacity to identify and track people with ASD and the services they receive across their lifespan.

TREATMENT (TT)
TT-1
Screen all children in Washington State for ASD before the age of three years, ideally by 18 months. To increase capacity, it is critical that all qualified health care providers and family resource coordinators be trained to administer the screenings.
TT-2
Screening, diagnosis, and referral to intervention for ASD and Asperger’s Syndrome must take place across the lifespan.
TT-3
All Washington State children birth to five years of age, diagnosed with ASD, or for whom ASD is suspected, must have access to a minimum of 25 hours a week of appropriate education services.
TT-4
All Washington students in kindergarten through 12th grade (and age 18-21 years when applicable) who may have ASD must have access to a minimum of 30 hours per week of appropriate educational services.
TT-5
Establish a minimum of one trained autism technical assistance specialist in each of the nine Educational Service Districts to provide support to teachers and staff.
TT-6
Adults with ASD must receive multidisciplinary supports, therapies, vocational assistance, and other services to assist them in developing and maintaining life skills and successful employment.
TT-7
Develop and implement appropriate education and support for all graduating students with ASD. Support must be defined and in place before a student leaves high school.
TT-8
All Washington adults with ASD must be provided with appropriate, publicly funded services to enable them to comply with the Working Age Adult Policy.

TT-9
Develop an Autism Services Guidebook that can be used as a resource directory for parents, organizations, and providers who serve individuals with ASD and their families, birth through the lifespan.

TT-10
Increase the availability of child and adult care providers who are able to serve individuals with ASD, particularly individuals over age 12.

TT-11
Provide appropriate wrap around services for individuals with ASD and their families, using ASD trained respite and personal care providers.

TT-12
Provide family preservation services and strategies to help families of individuals with ASD stay together.

TT-13
When out-of-home placement is necessary, provide families with a variety of options that are age appropriate, offer ASD trained staff, and are in an environment designed to meet the needs of the individuals served.

TRAINING (TG)

TG-1
Washington State must create a coordinated statewide training program to provide consistent, standardized and culturally effective training on ASD for individuals, families, educators, health care and all service providers.

TG-2
ASD training, including how to screen for and diagnose ASD, will be designed and provided especially for medical students, interns, pediatricians and family practice doctors.

TG-3
Provide ASD training designed especially for educators and allied health and human service professionals.

TG-4
Provide ASD training designed especially for first responders, including law enforcement.

TG-5
State emergency preparedness plans and trainings must incorporate awareness of the needs and possible behaviors of individuals with ASD during times of crisis.

FUNDING (F)

F-1
Where necessary, financing plans will be completed to initiate the recommendations found in this report.

F-2
Fund and enhance Regional Autism Centers of Excellence in targeted areas of the state to provide diagnostic services, therapies and training for parents and professionals; coordinate services currently available; and address gaps in services. (See IN-1)

F-3
Implement legislation that requires health insurance coverage of evidence-based interventions and services for individuals with ASD across the lifespan.

F-4
Fund community-based organizations that provide culturally effective parent and family support and resource information for families of individuals with ASD.
F-5
Create and fully fund a Medicaid home and community-based waiver to address the unique needs of children and adults with ASD.

F-6
Fully fund regular education and revise the cost accounting method used for special education safety net funding.

F-7
Create a student loan forgiveness program and explore other incentives to attract professionals in medicine, dentistry, and other allied health professions to work with individuals with ASD in our communities, schools, and clinics.

F-8
Create an Autism Awareness license plate and use proceeds from the sale to promote programs benefiting individuals with ASD.

F-9
Create tax incentives for Washington’s employers to provide meaningful employment opportunities for individuals with ASD.

Recommendations Organized by Relationship to Sub Committee Work

Recommendations Relating to Family Support

TT-3
All Washington State children birth to five years of age, diagnosed with ASD, or for whom ASD is suspected, must have access to a minimum of 25 hours a week of appropriate education services.

TT-4
All Washington students in kindergarten through 12th grade (and age 18-21 years when applicable) who may have ASD must have access to a minimum of 30 hours per week of appropriate educational services.

TT-9
Develop an Autism Services Guidebook that can be used as a resource directory for parents, organizations, and providers who serve individuals with ASD and their families, birth through the lifespan.

TT-10
Increase the availability of child and adult care providers who are able to serve individuals with ASD, particularly individuals over age 12.

TT-11
Provide appropriate wrap around services for individuals with ASD and their families, using ASD trained respite and personal care providers.

TT-12
Provide family preservation services and strategies to help families of individuals with ASD stay together.

TT-13
When out-of-home placement is necessary, provide families with a variety of options that are age appropriate, offer ASD trained staff, and are in an environment designed to meet the needs of the individuals served.

TG-4
Provide ASD training designed especially for first responders, including law enforcement.

TG-5
State emergency preparedness plans and trainings must incorporate awareness of the needs and possible behaviors of individuals with ASD during times of crisis.

F-1
Where necessary, financing plans will be completed to initiate the recommendations found in this report.
F-4
Fund community-based organizations that provide culturally effective parent and family support and resource information for families of individuals with ASD.

F-8
Create an Autism Awareness license plate and use proceeds from the sale to promote programs benefiting individuals with ASD.

Recommendations relating to Education/Training

IN-2
Ensure all individuals with ASD receive comprehensive health services and coverage within a Medical Home.

IN-4
Increase Washington State’s capacity to identify and track people with ASD and the services they receive across their lifespan.

TT-1
Screen all children in Washington State for ASD before the age of three years, ideally by 18 months. To increase capacity, it is critical that all qualified health care providers and family resource coordinators be trained to administer the screenings.

TT-3
All Washington State children birth to five years of age, diagnosed with ASD, or for whom ASD is suspected, must have access to a minimum of 25 hours a week of appropriate education services.

TT-4
All Washington students in kindergarten through 12th grade (and age 18-21 years when applicable) who may have ASD must have access to a minimum of 30 hours per week of appropriate educational services.

TT-5
Establish a minimum of one trained autism technical assistance specialist in each of the nine Educational Service Districts to provide support to teachers and staff.

TT-6
Adults with ASD must receive multidisciplinary supports, therapies, vocational assistance, and other services to assist them in developing and maintaining life skills and successful employment.

TT-7
Develop and implement appropriate education and support for all graduating students with ASD. Support must be defined and in place before a student leaves high school.

TT-8
All Washington adults with ASD must be provided with appropriate, publicly funded services to enable them to comply with the Working Age Adult Policy.

TT-10
Increase the availability of child and adult care providers who are able to serve individuals with ASD, particularly individuals over age 12.

TG-1
Washington State must create a coordinated statewide training program to provide consistent, standardized and culturally effective training on ASD for individuals, families, educators, health care and all service providers.

TG-2
ASD training, including how to screen for and diagnose ASD, will be designed and provided especially for medical students, interns, pediatricians and family practice doctors.

TG-3
Provide ASD training designed especially for educators and allied health and human service professionals.

TG-4
Provide ASD training designed especially for first responders, including law enforcement.
The document contains sections on priority recommendations and implementation plans. The recommendations are classified into different categories such as Emergency Preparedness, Funding, Education, and other related areas. Each recommendation is numbered and provides specific actions or strategies to be implemented. The implementation plans are designed to ensure that the recommendations are effectively carried out, with a focus on awareness, training, financing, and incentives for professionals.

Recommendations Relating to ID/Tracking

IN-2
Ensure all individuals with ASD receive comprehensive health services and coverage within a Medical Home.

IN-3
Contact will be initiated for persons with ASD by a service provider within 15 days of receiving a diagnosis.

IN-4
Increase Washington State’s capacity to identify and track people with ASD and the services they receive across their lifespan.

TT-1
Screen all children in Washington State for ASD before the age of three years, ideally by 18 months. To increase capacity, it is critical that all qualified health care providers and family resource coordinators be trained to administer the screenings.

TT-2
Screening, diagnosis, and referral to intervention for ASD and Asperger’s Syndrome must take place across the lifespan.

Recommendations Relating to Regional Centers

IN-1
Create and enhance Regional Autism Centers of Excellence in targeted areas of the state to provide diagnostic services, therapies, and training for parents and professionals; coordinate services currently available; and address gaps in services.

IN-2
Ensure all individuals with ASD receive comprehensive health services and coverage within a Medical Home.

IN-3
Contact will be initiated for persons with ASD by a service provider within 15 days of receiving a diagnosis.
TT-1
Screen all children in Washington State for ASD before the age of three years, ideally by 18 months. To increase capacity, it is critical that all qualified health care providers and family resource coordinators be trained to administer the screenings.

TT-6
Adults with ASD must receive multidisciplinary supports, therapies, vocational assistance, and other services to assist them in developing and maintaining life skills and successful employment.

TT-10
Increase the availability of child and adult care providers who are able to serve individuals with ASD, particularly individuals over age 12.

TT-11
Provide appropriate wrap around services for individuals with ASD and their families, using ASD trained respite and personal care providers.

TT-12
Provide family preservation services and strategies to help families of individuals with ASD stay together.

TG-1
Washington State must create a coordinated statewide training program to provide consistent, standardized and culturally effective training on ASD for individuals, families, educators, health care and all service providers.

TG-2
ASD training, including how to screen for and diagnose ASD, will be designed and provided especially for medical students, interns, pediatricians and family practice doctors.

TG-3
Provide ASD training designed especially for educators and allied health and human service professionals.

F-1
Where necessary, financing plans will be completed to initiate the recommendations found in this report.

F-2
Fund and enhance Regional Autism Centers of Excellence in targeted areas of the state to provide diagnostic services, therapies and training for parents and professionals; coordinate services currently available; and address gaps in services. (See IN-1)

F-3
Implement legislation that requires health insurance coverage of evidence-based interventions and services for individuals with ASD across the lifespan.

F-5
Create and fully fund a Medicaid home and community-based waiver to address the unique needs of children and adults with ASD.

F-7
Create a student loan forgiveness program and explore other incentives to attract professionals in medicine, dentistry, and other allied health professions to work with individuals with ASD in our communities, schools, and clinics.
Six Selected Priority Recommendations 2007

- Ensure all individuals with ASD receive comprehensive health services and coverage within a medical home.

- Create and enhance existing Regional Autism Centers of Excellence in targeted areas of the state to (1) provide diagnostic services, therapies, and training for parents and professionals; (2) coordinate services currently available; and (3) address gaps in services.

- Screen all children in Washington State for ASD before the age of 3 years, ideally by 18 months. To increase capacity, it is critical that all qualified health care providers and family resource coordinators be trained to administer the screenings. Screening, diagnosis, and referral to intervention for ASD and Asperger’s Syndrome must take place across the lifespan.*

- Provide family preservation services and strategies to help families of individuals with ASD stay together. When out-of-home placement is necessary, provide families with a variety of options that are age appropriate, offer ASD trained staff, and are in an environment designed to meet the needs of the individuals served.*

- Establish a minimum of one trained autism technical assistance specialist in each of the nine Education Service Districts to provide support to teachers and staff.

- Develop an Autism Services Guidebook that can be used as a resource directory for parents, organizations, and providers who serve individuals with ASD and their families, birth through the lifespan. Create an Autism Awareness license plate and use proceeds from the sale to promote programs benefiting individuals with ASD.*

*Some recommendations of the original 31 from Caring for Washington Individuals With Autism Task Force Report 2006 were combined in subcommittee work process
# Appendix Six

## Autism Task Force Fiscal Estimate

This estimate is for one year of continuing the Autism Task Force. Costs for additional years are not reflected. This includes a state agency indirect rate of 20%; indirect rates will vary depending on the agency receiving the funds and how those funds will be used.

<table>
<thead>
<tr>
<th>Budget Categories</th>
<th>Year 1</th>
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<tbody>
<tr>
<td><strong>Personnel</strong></td>
<td></td>
</tr>
<tr>
<td>• Project Coordinator (1.0 FTE Health Services Consultant 3, salary range 56)</td>
<td>60,420</td>
</tr>
<tr>
<td>Responsible for overseeing and coordinating statewide coalition for Regional Networks vision; reports.</td>
<td></td>
</tr>
<tr>
<td>• Administrative Support (0.5 FTE Secretary Senior at salary range 33)</td>
<td>17,178</td>
</tr>
<tr>
<td>Reports to Project Coordinator. Responsible for administrative support to Project Coordinator and Regional subcommittee including logistics of meetings, tracking budget, contracts.</td>
<td></td>
</tr>
<tr>
<td><strong>Benefits</strong></td>
<td></td>
</tr>
<tr>
<td>• Project Coordinator</td>
<td>17,825</td>
</tr>
<tr>
<td>• Administrative Support</td>
<td>5,067</td>
</tr>
<tr>
<td>Components include unemployment insurance, life insurance, taxes social security, health care insurance and retirement.</td>
<td></td>
</tr>
<tr>
<td><strong>Travel</strong></td>
<td>16,506</td>
</tr>
<tr>
<td>• Basic FTE travel expenses ($3,306)</td>
<td></td>
</tr>
<tr>
<td>• Regional Subcommittee meeting travel and expenses once a month, at $1,100 each meeting with 10-15 participants. ($1,100 x 12 = $13,200)</td>
<td></td>
</tr>
<tr>
<td>Projected travel costs based on state government travel rates by destination and per diem schedules, agency average by FTE and the average cost of meetings from past meetings.</td>
<td></td>
</tr>
<tr>
<td><strong>Equipment</strong></td>
<td>0</td>
</tr>
<tr>
<td>Property at $5,000 or above will not be purchased</td>
<td></td>
</tr>
<tr>
<td><strong>Supplies</strong></td>
<td>14,189</td>
</tr>
<tr>
<td>• General office supplies include materials to maintain daily operations such as pencils, paper, and meeting materials. ($1,309)</td>
<td></td>
</tr>
<tr>
<td>• FTE (2) associated work-site stations includes computer, monitor, ergo chair and desk set-up. ($12,174)</td>
<td></td>
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<tr>
<td>Projected costs based on agency averages.</td>
<td></td>
</tr>
<tr>
<td>Budget Categories</td>
<td>Year 1</td>
</tr>
<tr>
<td>-------------------------------------------------------</td>
<td>--------</td>
</tr>
<tr>
<td>Other</td>
<td>28,174</td>
</tr>
<tr>
<td>Administrative costs not included in any other category or agency indirect</td>
<td></td>
</tr>
<tr>
<td>- Staff work-site rent, facility maintenance, facility services, communications, phones, scanning, fax, postage, printing, employee training, and agency information technology computer supports, software, data base, internet systems and web-site enhancements. Projected costs are based on required state agency charges and averages over past 2-years.</td>
<td></td>
</tr>
<tr>
<td>Personal Service Contracts</td>
<td>16,500</td>
</tr>
<tr>
<td>- Parent Stipends ($6,000). Projection based on 2 parents, up to $200 each per meeting for 15 meetings ($200 x 2 x 15 = $6,000)</td>
<td></td>
</tr>
<tr>
<td>- Professional Facilitator ($10,500). Projection based 7 meetings at $1,500 each.</td>
<td></td>
</tr>
<tr>
<td>Sub-total</td>
<td>175,859</td>
</tr>
<tr>
<td>Indirect rate</td>
<td>35,172</td>
</tr>
<tr>
<td>Total</td>
<td>$211,031</td>
</tr>
</tbody>
</table>
Coalition Staffing Fiscal Estimate

Estimated costs for 1 year to support a planning period to establish a statewide coalition of regional networks. This includes a state agency indirect rate of 20%; indirect rates will vary depending on the agency receiving the funds and how those funds will be used. Future costs for continued coordination of the coalition or costs specific to expanding regional hubs will be determined by the coalition.

<table>
<thead>
<tr>
<th>Budget Categories</th>
<th>Year 1</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Personnel</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Project Coordinator</strong> (1.0 FTE at state employee salary range 56)</td>
<td>60,420</td>
</tr>
<tr>
<td>Responsible for overseeing and coordinating the formation of a statewide coalition for ASD and related disorders.</td>
<td></td>
</tr>
<tr>
<td><strong>Administrative Support</strong> (0.5 FTE at state employee salary range 33)</td>
<td>17,178</td>
</tr>
<tr>
<td>Reports to Project Coordinator. Responsible for administrative support to Project Coordinator and planning committee including logistics of meetings, tracking budget, contracts.</td>
<td></td>
</tr>
<tr>
<td><strong>Benefits</strong></td>
<td>17,825</td>
</tr>
<tr>
<td>• Project Coordinator</td>
<td>5,067</td>
</tr>
<tr>
<td>• Administrative Support</td>
<td></td>
</tr>
<tr>
<td>Components include unemployment insurance, life insurance, taxes social security, health care insurance and retirement.</td>
<td></td>
</tr>
<tr>
<td><strong>Travel</strong></td>
<td>3,306</td>
</tr>
<tr>
<td>• Basic FTE travel expenses</td>
<td>13,200</td>
</tr>
<tr>
<td>• Regional Subcommittee meeting travel and expenses once a month, at $1,100 each meeting with 10-15 participants.</td>
<td></td>
</tr>
<tr>
<td>Projected travel and meeting costs are based on state government travel rates by destination and per diem schedules, Department of Health (DOH) average by FTE, and the average cost of meetings from past meetings. Travel and meeting costs could vary if another agency provides staff support.</td>
<td></td>
</tr>
<tr>
<td><strong>Equipment</strong></td>
<td>0</td>
</tr>
<tr>
<td>Property at $5,000 or above will not be purchased</td>
<td></td>
</tr>
<tr>
<td><strong>Supplies</strong></td>
<td>1,309</td>
</tr>
<tr>
<td>• General office supplies include materials to maintain daily operations such as pencils, paper, and meeting materials.</td>
<td></td>
</tr>
<tr>
<td>• FTE (2) associated work-site stations includes computer, monitor, ergonomic chair and desk set-up.</td>
<td></td>
</tr>
<tr>
<td>Projected costs based on DOH averages; this could vary if another agency provides staff support.</td>
<td></td>
</tr>
<tr>
<td><strong>Other</strong></td>
<td>28,174</td>
</tr>
<tr>
<td>Costs not included in any other category or agency indirect</td>
<td></td>
</tr>
</tbody>
</table>
Caring for Washington Individuals with Autism Task Force

**Budget Categories**

<table>
<thead>
<tr>
<th>Budget Categories</th>
<th>Year 1</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Staff work-site rent, facility maintenance, facility services, communications, phones, scanning, fax, postage, printing, employee training, and agency information technology computer supports, software, data base, internet systems and web-site enhancements.</td>
<td></td>
</tr>
<tr>
<td>Projected costs are based on required DOH agency charges and averages over past 2-years. These could vary if another agency provides staff support.</td>
<td></td>
</tr>
<tr>
<td><strong>Sub-Total</strong></td>
<td>$159,359</td>
</tr>
<tr>
<td><strong>Indirect rate 20%</strong></td>
<td>$31,872</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>$191,231</strong></td>
</tr>
</tbody>
</table>
Regional Needs Assessment Fiscal Estimate

Estimated costs for 1 year to support a contract to conduct five regional needs assessments. This includes a state agency indirect rate of 20%; indirect rates will vary depending on the agency receiving the funds and how those funds will be used. Future costs for continued coordination of the coalition or costs specific to expanding regional hubs will be determined by the coalition.

<table>
<thead>
<tr>
<th>Needs Assessment</th>
<th>Year 1</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Anticipated scope of work for contract</strong></td>
<td>40,000</td>
</tr>
<tr>
<td>• Meeting with ATF and state agency staff in Olympia to clarify needs</td>
<td>x 5</td>
</tr>
<tr>
<td>• Collecting information on services for individuals with autism in five regions</td>
<td>= 200,000</td>
</tr>
<tr>
<td>of the state (Tacoma, Vancouver, Tri-Cities, Yakima, &amp; Spokane) via:</td>
<td></td>
</tr>
<tr>
<td>• two family focus groups</td>
<td></td>
</tr>
<tr>
<td>• one care provider focus group</td>
<td></td>
</tr>
<tr>
<td>• medical provider key informant interviews (estimated 10 providers per region)</td>
<td></td>
</tr>
<tr>
<td>• medical facility key informant interviews (estimated 5 facilities per region)</td>
<td></td>
</tr>
<tr>
<td>• Development and presentation of final report in Olympia</td>
<td></td>
</tr>
<tr>
<td>Estimated costs ($40,000 per region) include: project design, recruiting,</td>
<td></td>
</tr>
<tr>
<td>moderating/interviewing, audio taping sessions, provision of transcripts,</td>
<td></td>
</tr>
<tr>
<td>incentivizing participants, and all reporting activities. Costs assume that</td>
<td></td>
</tr>
<tr>
<td>contractor would not need to rent space to conduct sessions and that the ATF</td>
<td></td>
</tr>
<tr>
<td>and coordinating state agency will assist with identifying sample sources for</td>
<td></td>
</tr>
<tr>
<td>recruitment purposes and writing letters to inform recruits about the project.</td>
<td></td>
</tr>
</tbody>
</table>

| Personnel                                                                      | $12,084 |
| • .20 FTE at state salary range 56 to manage contract, oversee work, and        |        |
| be a liaison to the staff of the ATF and the statewide coalition for ASD and     |        |
| related disorders.                                                             |        |

| Benefits                                                                      | $3,411  |
| • Components include unemployment insurance, life insurance, taxes social      |        |
| security, health care insurance and retirement.                               |        |

| Travel                                                                        | $600    |
| • Basic FTE travel expenses                                                   |        |
| Projected travel and meeting costs are based on state government travel       |        |
| rates by destination and per diem schedules, Department of Health (DOH)       |        |
| average by FTE, and the average cost of meetings from past meetings. Travel   |        |
| and meeting costs could vary if another agency provides staff support.        |        |
### Needs Assessment

<table>
<thead>
<tr>
<th>Supplies</th>
<th>Year 1</th>
</tr>
</thead>
<tbody>
<tr>
<td>General office supplies include materials to maintain daily operations such as pencils, paper, and meeting materials.</td>
<td>$2,795</td>
</tr>
<tr>
<td>FTE associated work-site stations includes computer, monitor, ergonomic chair and desk set-up. Projected costs based on DOH averages; this could vary if another agency provides staff support.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Other</th>
<th>Year 1</th>
</tr>
</thead>
<tbody>
<tr>
<td>Costs not included in any other category or agency indirect</td>
<td>$6,292</td>
</tr>
<tr>
<td>Staff work-site rent, facility maintenance, facility services, communications, phones, scanning, fax, postage, printing, employee training, and agency information technology computer supports, software, data base, internet systems and web-site enhancements. Projected costs are based on required DOH agency charges and averages over past 2-years. These could vary if another agency provides staff support.</td>
<td></td>
</tr>
</tbody>
</table>

| Sub-Total | $225,182 |
| Indirect rate 20% | $45,036 |
| Total | $270,218 |
### Fiscal Estimate for Training, Education, and Media to Increase Awareness of Autism and Provider Knowledge to Improve Screening for Autism

The following provides three options and different levels of funding to support training, education, and media to increase awareness of autism and provider knowledge. This includes a state agency indirect rate of 20%; indirect rates will vary depending on the agency receiving the funds and how those funds will be used. Costs are for one year, but are expected to continue in the future. Fiscal needs may be different after the first year and will need to be determined by the Washington Coalition for ASD and Related Disorders.

<table>
<thead>
<tr>
<th>Option 1</th>
<th>Year 1</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Option 1 includes:</strong></td>
<td>$530,000</td>
</tr>
<tr>
<td>• Statewide press campaign</td>
<td>Plus 20%</td>
</tr>
<tr>
<td>• Television public service announcements</td>
<td><strong>Total =</strong></td>
</tr>
<tr>
<td>• Creating, printing, and distributing 115,000 brochures for parents</td>
<td>$636,000</td>
</tr>
<tr>
<td>• Six regional trainings offering continued medical education (CME) credits, three train the trainer workshops, and 12 mailings</td>
<td></td>
</tr>
<tr>
<td>• Thirty Grand Rounds presentations</td>
<td></td>
</tr>
<tr>
<td>• 1,000 screening kits tailored for Washington</td>
<td></td>
</tr>
<tr>
<td>• Dedicated resource page on <em>First Signs</em> Web site</td>
<td></td>
</tr>
<tr>
<td>• Archive Webcasts for 1 year</td>
<td></td>
</tr>
<tr>
<td>• Dedicated Washington Coordinator</td>
<td></td>
</tr>
<tr>
<td>• Evaluation study (short and long term)</td>
<td></td>
</tr>
<tr>
<td>• Creating Web-based materials for providers and expanding state Medical Home Web site to include information about autism</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Option 2 (recommended)</th>
<th>Year 1</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Option 2 includes:</strong></td>
<td>$410,000</td>
</tr>
<tr>
<td>• Statewide press campaign</td>
<td>Plus 20%</td>
</tr>
<tr>
<td>• Television public service announcements</td>
<td><strong>Total =</strong></td>
</tr>
<tr>
<td>• Creating, printing, and distributing 115,000 brochures for parents</td>
<td>$492,000</td>
</tr>
<tr>
<td>• Six regional trainings offering continued medical education (CME) credits, two train the trainer workshops, and four mailings</td>
<td></td>
</tr>
<tr>
<td>• Thirty Grand Rounds presentations</td>
<td></td>
</tr>
<tr>
<td>• 1,000 screening kits tailored for Washington</td>
<td></td>
</tr>
<tr>
<td>• Dedicated resource page on <em>First Signs</em> Web site</td>
<td></td>
</tr>
<tr>
<td>• Dedicated Washington Coordinator</td>
<td></td>
</tr>
<tr>
<td>• Evaluation study (short and long term)</td>
<td></td>
</tr>
<tr>
<td>• Creating Web-based materials for providers and expanding state Medical Home Web site to include information about autism</td>
<td></td>
</tr>
<tr>
<td>Option 3</td>
<td>Year 1</td>
</tr>
<tr>
<td>------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Option 3 includes:</td>
<td>$310,000</td>
</tr>
<tr>
<td>- Statewide press campaign</td>
<td>Plus 20%</td>
</tr>
<tr>
<td>- Television public service announcements</td>
<td><strong>Total</strong> $372,000</td>
</tr>
<tr>
<td>- Creating, printing, and distributing 75,000 brochures for parents</td>
<td></td>
</tr>
<tr>
<td>- Four regional trainings offering continued medical education (CME)</td>
<td></td>
</tr>
<tr>
<td>credits, two train the trainer workshops, and 2 mailings</td>
<td></td>
</tr>
<tr>
<td>- Thirty Grand Rounds presentations</td>
<td></td>
</tr>
<tr>
<td>- 700 screening kits tailored for Washington</td>
<td></td>
</tr>
<tr>
<td>- Dedicated resource page on <em>First Signs</em> Web site</td>
<td></td>
</tr>
<tr>
<td>- Dedicated Washington Coordinator</td>
<td></td>
</tr>
<tr>
<td>- Evaluation study (short and long term)</td>
<td></td>
</tr>
<tr>
<td>- Creating Web-based materials for providers and expanding state</td>
<td></td>
</tr>
<tr>
<td>Medical Home Web site to include information about autism</td>
<td></td>
</tr>
</tbody>
</table>

**Note:** Costs may be reduced by local coordination, evaluation coordinated through state universities, and use of the train the trainer model. Given available Washington State resources, Option 2 is recommended by the ID/Tracking Subcommittee.
Autism Family Care Fiscal Estimate

The following represents 1 year of funding to increase current Autism Family Specialist help line staffing. We anticipate the need for this funding to be ongoing and costs to increase overtime as cost of living salary increases are added. This includes a state agency indirect rate of 20%; indirect rates will vary depending on the agency receiving the funds and how those funds will be used.

<table>
<thead>
<tr>
<th>Budget Categories</th>
<th>Year 1 and ongoing</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Office of Superintendent of Public Instruction</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Personnel</strong></td>
<td></td>
</tr>
<tr>
<td>Statewide Autism Outreach Project Family Specialist (Increase existing position to 1 FTE). Responsible for providing information and referrals, resources, and support over the phone.</td>
<td>40,000</td>
</tr>
<tr>
<td><strong>Benefits</strong></td>
<td></td>
</tr>
<tr>
<td>For 1 FTE at 29.5%</td>
<td>11,200</td>
</tr>
<tr>
<td><strong>Northwest Autism Center</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Personnel</strong></td>
<td></td>
</tr>
<tr>
<td>Northwest Autism Center Family Support Person (Increase existing position to 1 FTE). Responsible for providing information and referrals, resources, and support over the phone.</td>
<td>40,000</td>
</tr>
<tr>
<td><strong>Benefits</strong></td>
<td></td>
</tr>
<tr>
<td>For 1 FTE at 28%</td>
<td>11,200</td>
</tr>
<tr>
<td><strong>Autism Society of Washington</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Personnel</strong></td>
<td></td>
</tr>
<tr>
<td>Autism Society of Washington Support line (Increase existing position to 1 FTE). Responsible for providing information and referrals, resources, and support over the phone.</td>
<td>40,000</td>
</tr>
<tr>
<td><strong>Benefits</strong></td>
<td></td>
</tr>
<tr>
<td>For 1 FTE at 28%</td>
<td>11,200</td>
</tr>
<tr>
<td><strong>University of Washington Autism Center</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Personnel</strong></td>
<td></td>
</tr>
<tr>
<td>Support line staff (continue 1 FTE). Responsible for providing information and referrals, resources, and support over the phone.</td>
<td>40,000</td>
</tr>
<tr>
<td><strong>Benefits</strong></td>
<td></td>
</tr>
<tr>
<td>For 1 FTE at 28%</td>
<td>11,200</td>
</tr>
</tbody>
</table>
## Budget Categories

<table>
<thead>
<tr>
<th>Parent to Parent</th>
<th>Year 1 and ongoing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Funding to Parent to Parent statewide organization to support increased capacity to provide support to parents of children with autism. Responsible for providing information and referrals, resources, and support over the phone.</td>
<td>40,000</td>
</tr>
<tr>
<td><strong>Sub-Total</strong></td>
<td><strong>244,800</strong></td>
</tr>
<tr>
<td><strong>Indirect rate 20%</strong></td>
<td><strong>48,960</strong></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>$293,760</strong></td>
</tr>
</tbody>
</table>
**Autism Education Network Coordinator Fiscal Estimate**

The following represents 1 year of funding to expand the present model of the Autism Education Network Coordinator and Regional Autism Consulting Cadre Coordinator to all nine regional state Educational Service Districts (ESDs) & increased funding to support the current Autism Outreach Project (OSPI). We anticipate the need for this funding to be ongoing and costs to increase overtime as cost of living salary increases are added. This includes a state agency indirect rate of 20%; indirect rates will vary depending on the agency receiving the funds and how those funds will be used.

<table>
<thead>
<tr>
<th>Budget Categories</th>
<th>Year 1 and ongoing</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Personnel (ESDs)</strong></td>
<td></td>
</tr>
<tr>
<td>Autism Education Network Coordinator or Regional Autism Consulting Cadre Coordinator (1 FTE based on NWESD salary range III.8)</td>
<td>70,000</td>
</tr>
<tr>
<td>Administrative Support (0.55 FTE)</td>
<td>20,000</td>
</tr>
<tr>
<td><strong>Benefits (ESDs)</strong></td>
<td></td>
</tr>
<tr>
<td>Autism Education Network Coordinator or Regional Autism Consulting Cadre Coordinator (1 FTE)</td>
<td>21,000</td>
</tr>
<tr>
<td>Administrative Support (0.55 FTE)</td>
<td>10,100</td>
</tr>
<tr>
<td><strong>Travel</strong></td>
<td></td>
</tr>
<tr>
<td>Regional and statewide travel as needed</td>
<td>15,000</td>
</tr>
<tr>
<td><strong>Equipment</strong></td>
<td></td>
</tr>
<tr>
<td>Property at $5,000 or above will not be purchased</td>
<td></td>
</tr>
<tr>
<td><strong>Supplies</strong></td>
<td></td>
</tr>
<tr>
<td>General office supplies, software and licenses, postage, and instructional materials</td>
<td>7,380</td>
</tr>
<tr>
<td>Computers, cell phone, and PDA</td>
<td>4,000</td>
</tr>
<tr>
<td><strong>Contractual Services</strong></td>
<td></td>
</tr>
<tr>
<td>Contractual services, technology support fees, space rental, advertising, membership fees, subscriptions, meeting room rent, registration fees, office space allocation, video conferencing, copying and printing</td>
<td>39,700</td>
</tr>
<tr>
<td><strong>Total for nine ESDs (187,180 x 9)</strong></td>
<td>1,684,620</td>
</tr>
<tr>
<td>Budget Categories</td>
<td>Year 1 and ongoing</td>
</tr>
<tr>
<td>--------------------------------------------------------</td>
<td>--------------------</td>
</tr>
<tr>
<td><strong>Personnel (OSPI-Autism Outreach Project)</strong></td>
<td></td>
</tr>
<tr>
<td>● Autism Network Manager/Administrator (1 FTE based on NWESD salary range III.9 to III.10)</td>
<td>75,000</td>
</tr>
<tr>
<td>● Administrative Support (1 FTE)</td>
<td>36,000</td>
</tr>
<tr>
<td>● Parent Education Specialist (.7 FTE based on NWESD salary range III.2)</td>
<td>40,000</td>
</tr>
<tr>
<td><strong>Benefits (OSPI-Autism Outreach Project)</strong></td>
<td></td>
</tr>
<tr>
<td>● Autism Network Manager/Administrator</td>
<td>22,300</td>
</tr>
<tr>
<td>● Administrative Support</td>
<td></td>
</tr>
<tr>
<td>Family Education Specialist</td>
<td>12,000</td>
</tr>
<tr>
<td></td>
<td>15,300</td>
</tr>
<tr>
<td><strong>Travel</strong></td>
<td></td>
</tr>
<tr>
<td>National &amp; statewide as needed</td>
<td>20,000</td>
</tr>
<tr>
<td><strong>Equipment</strong></td>
<td></td>
</tr>
<tr>
<td>Property at $5,000 or above will not be purchased</td>
<td>0</td>
</tr>
<tr>
<td><strong>Supplies</strong></td>
<td></td>
</tr>
<tr>
<td>General office supplies, software and licenses, postage, and instructional materials</td>
<td>10,000</td>
</tr>
<tr>
<td>Computers, cell phone, and PDA (upgrade existing)</td>
<td>3,000</td>
</tr>
<tr>
<td><strong>Contractual Services</strong></td>
<td></td>
</tr>
<tr>
<td>Contractual services, technology support fees, space rental, advertising, membership fees, subscriptions, meeting room rent, registration fees, office space allocation, video conferencing, copying and printing</td>
<td>44,700</td>
</tr>
<tr>
<td><strong>Total for OSPI-Autism Outreach Project</strong></td>
<td>278,300</td>
</tr>
<tr>
<td><strong>Sub-Total estimate for nine ESDs and OSPI</strong></td>
<td>1,962,920</td>
</tr>
<tr>
<td><strong>Indirect rate 20%</strong></td>
<td>392,584</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>$2,355,504</td>
</tr>
</tbody>
</table>
# Appendix Seven

## Table: Current Regional Hubs (Demonstration Sites)

<table>
<thead>
<tr>
<th>DEMONSTRATION SITES/MODELS</th>
<th>ESTABLISHED</th>
<th>FUNDING</th>
<th>SERVICES</th>
<th>CAPACITY</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Seattle-Tacoma Region</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| UW Autism Center               | Seattle/ 2000   | Private/ Federal/Grant| ● Training & resources to school districts, early intervention providers, parents, other agencies  
  ○ Multidisciplinary diagnostic and treatment services  
    ○ psychology  
    ○ psychiatry  
    ○ developmental pediatrics  
    ○ early intervention  
    ○ occupational therapy  
    ○ speech therapy  
    ○ sleep and GI (gastrointestinal) consultation  
  ● Training of psychology/psychiatry fellows; pediatric fellows, allied health professionals (OT and speech), teachers, medical students and medical residents  
  ● Grant funded research programs  
  ● Regional resources provided | ● Consultation to 10 school districts  
  ● 600 children served at Seattle site  
  ● 200 children and families served at Tacoma site  
  ● 20,000 hours total direct services including 16,000 hours of behavioral intervention  
  ● 90 trainees across disciplines in the past six years  
  ● Responded to 7,000 calls for resources |
|                               | Tacoma/ 2003    | State Private        |                                                                            |                                                                            |
|                               |                 |                      |                                                                            |                                                                            |
| **Spokane Region**             |                 |                      |                                                                            |                                                                            |
| NAC’s Domino Preschool        | NAC est. 2003   | Northwest Autism     | ● Training and resources to school districts, providers  
  (ancillary services, physicians, nurses, child and adult home care providers, dentists, etc.….)  
  ● Early intervention (year-round inclusive preschool) includes:  
    ○ Home visits  
    ○ Speech therapy  
    ○ Psychiatric consultation  
    ○ Psychology consult  
    ○ Parent training  
  ● Student practicum experiences in related fields (ie., speech and education).  
  ● Work study opportunities for EWU students  
  ● Information and referral services for community (parents, providers, individuals with autism, the media, local agencies, etc.….)  
  ● Website with updated information and articles on autism for variety of disciplines and parents | ● 850 contacts (90% from families, 10% providers – increase almost triple from last year)  
  ● 80% result in follow-up calls from families  
  ● Part time staff works volunteer hours to prevent waiting list  
  ● 500 served by presentations (triple increase from last year)  
  ● 12 children served at preschool (6 on the spectrum).  
  ● Waiting list unknown – Domino is closed program due to funding limits.  
  ● Only one developmental pediatrician in Spokane (at SHMC Children’s Hospital). 6 month waiting list. Lack of funding |
|                               | 2005            | University (EWU) and  |                                                                            |                                                                            |
|                               |                 | Sacred Heart Children’s Hospital for work on Domino Project (preschool intervention program) |                                                                            |                                                                            |

Note: SHMC = Sacred Heart Medical Children’s Hospital.
<table>
<thead>
<tr>
<th>DEMONSTRATION SITES/MODELS</th>
<th>ESTABLISHED</th>
<th>FUNDING</th>
<th>SERVICES</th>
<th>CAPACITY</th>
</tr>
</thead>
</table>
| Yakima Region Children’s Village | Family support, Motor and Speech Therapy, Behavioral Assessment Intervention Education in Yakima and Sunnyside/1997 | State/Federal, Private and Grant Yakima Valley Memorial Hospital | Central location for families with children with disabilities to access resource information and services Integrated Services and Early Intervention  
- Family support  
- Recreational activities  
- Occupational & physical therapy  
- Aqua therapy & Hippotherapy  
- Speech language therapy  
- Behavioral intervention  
- Education  
- Family resource coordination  
- Social Skill groups  
- Medical Specialty Clinics  
- Mental Health Counseling  
- Nutrition  
- Dental  
- Early Head start Diagnostic Team (Autism Diagnostic Observation Schedule)(ADOS)  
- Neurodevelopmental Pediatrician  
- Psychologist  
- Speech Language Pathologist  
- Behavioral Health Therapist Training and consultation services:  
- School personnel  
- Childcare providers  
- CWU (Central Washington University) psychology/special ed students  
- Parents Collaborative Classroom (6 students)  
- Individualized intensive, programming  
- Transition planning | 1 year timeframe  
- Served/Waitlist  
- Prevents development of diagnostic team for autism in collaboration with SHMC.  
- No funding or coverage for hiring intervention service provider, and only one in private practice in Spokane, infinite wait list.  
- Estimated 500 children in Yakima County with ASD  
- Estimated currently serving 75 children |
<table>
<thead>
<tr>
<th>DEMONSTRATION SITES/MODELS</th>
<th>ESTABLISHED</th>
<th>FUNDING</th>
<th>SERVICES</th>
<th>CAPACITY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vancouver Region</td>
<td>1998</td>
<td>Division of Developmental Disabilities, grants and private donation</td>
<td>Training and resources to 9 school districts (141 schools)</td>
<td>Training Capacity only</td>
</tr>
<tr>
<td>Regional Autism Consulting Cadre</td>
<td></td>
<td></td>
<td>Teachers, OT (Occupational Therapy), SLP (Speech/Language Therapy), School Psychologist, Parents, Agency Representation throughout Birth to Transition in the ESD 112 Region of SW Washington.</td>
<td></td>
</tr>
<tr>
<td>Autism Community Services (nonprofit)</td>
<td></td>
<td></td>
<td>Family directed whole life services for 13 families in Southwest Washington; Voluntary Placement Programs, Companion Homes, Advocacy, Community Autism Awareness, Comprehensive Life Planning.</td>
<td></td>
</tr>
<tr>
<td>Tri-Cities Region</td>
<td>ASW – 2002 Coalition - 2005</td>
<td>CDC funding through DDD. Birth to three program.</td>
<td>Occupational Therapy/Physical Therapy and Speech Therapy through our Hospitals.</td>
<td>Currently serving an estimated 45 children</td>
</tr>
<tr>
<td>Tri-Cities Autism Coalition</td>
<td></td>
<td></td>
<td>One diagnostician that is insurance and private pay but doesn’t accept the medical coupon.</td>
<td>Five month waiting list for diagnostic appointments/only one diagnostician.</td>
</tr>
<tr>
<td>Southwest Washington 3-River Autism Center</td>
<td></td>
<td></td>
<td>Children’s Developmental Center has a birth to 3 program for children with autism.</td>
<td>Currently serves 12 students.</td>
</tr>
<tr>
<td>Autism Society of Washington/Tri-Cities Chapter (ASW-TCC)</td>
<td></td>
<td></td>
<td>Most of our school districts have an autism program.</td>
<td>ASW/TCC parent support group has 300+ community members, who either attend monthly meetings or receive e-mail and go to the local website for information</td>
</tr>
<tr>
<td>Neurological Resource Center</td>
<td></td>
<td></td>
<td>Some of them are at capacity and some are in the infant stages of development.</td>
<td></td>
</tr>
<tr>
<td>WSU-Tri-Cities</td>
<td></td>
<td></td>
<td>All school districts have a speech, PT and OT individual and all of them offer minimal services to children on the autism spectrum.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>No site specific center at this time that delivers autism services, however a very strong autism support group.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Neurological Resource Center provides some ASD education to the public, collaborates with others to host the Southeastern Autism Conference, and has a lending library.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Tri-Cities Autism Coalition looking at model of Children’s Village.</td>
<td></td>
</tr>
</tbody>
</table>
Organizational Structure of Hubs to Local Region, State Coalition, Task Force

- Autism Task Force; Original Members and Recommendations
- WA Coalition, State & Local Agencies: Create a Plan
- DOH DSHS; DDD, MHD
- Local Coalition: Local Agencies & WA Coalition Reps: Local Planning
- Local Regional Network

- **HUB:** Tri-Cities
- **HUB:** Yakima
- **HUB:** Spokane
- **HUB:** Seattle Tacoma
- **HUB:** Vancouver
# Appendix Eight

## Glossary

For the purposes of this report, the following definitions were used by the Autism Task Force.

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appropriate Services</td>
<td>Services that are timely, individualized, culturally effective, multidisciplinary, evidence based, and legally required.</td>
</tr>
<tr>
<td>Autism Spectrum Disorder (ASD)</td>
<td>ASDs include autistic disorder, pervasive developmental disorder - not otherwise specified (PDD-NOS, including atypical autism), and Asperger syndrome. These conditions all have some of the same symptoms, but they differ in terms of when the symptoms start, how severe they are, and the exact nature of the symptoms. The three conditions, along with Rett syndrome and childhood disintegrative disorder, make up the broad diagnosis category of pervasive developmental disorders</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>There is no medical test for autism and related disorders. Diagnosis is typically made after a thorough evaluation which includes physical, neurological and possibly genetic testing.</td>
</tr>
<tr>
<td>Screening Tools</td>
<td>There are several screening instruments that have been developed that are now used in diagnosing autism. These include Childhood Autism Rating Scale (CARS), The Checklist for Autism in Toddlers (CHAT), and The Autism Screening Questionnaire.</td>
</tr>
<tr>
<td>Related Disorders</td>
<td>Autism is often grouped with similar disorders, all of which may be referred to collectively as autism spectrum disorders (ASD). ASD refers to the entire autism spectrum, including autism, Asperger syndrome, childhood disintegrative disorder, Rett syndrome, and pervasive developmental disorders not otherwise specified.</td>
</tr>
</tbody>
</table>
## Appendix Nine

### Autism Task Force Acronyms

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>AAP</td>
<td>American Academy of Pediatrics</td>
</tr>
<tr>
<td>ABA</td>
<td>Applied Behavior Analyst</td>
</tr>
<tr>
<td>ADA</td>
<td>Americans with Disabilities Act (or Association)</td>
</tr>
<tr>
<td>ADDMN</td>
<td>Autism and Developmental Disabilities Monitoring Network</td>
</tr>
<tr>
<td>ADOS</td>
<td>Autism Diagnostic Observation Schedule</td>
</tr>
<tr>
<td>ADSA</td>
<td>Aging and Disability Services Administration</td>
</tr>
<tr>
<td>AEC</td>
<td>Autism Education Coordinator</td>
</tr>
<tr>
<td>AENC</td>
<td>Autism Education Network Coordinator</td>
</tr>
<tr>
<td>AOP</td>
<td>Autism Outreach Project</td>
</tr>
<tr>
<td>ASA</td>
<td>Autism Society of America</td>
</tr>
<tr>
<td>ASD</td>
<td>Autism Spectrum Disorder</td>
</tr>
<tr>
<td>ASW</td>
<td>Autism Society of Washington</td>
</tr>
<tr>
<td>ATF</td>
<td>Autism Task Force</td>
</tr>
<tr>
<td>BCBA</td>
<td>Board Certified Behavior Analyst</td>
</tr>
<tr>
<td>CAC</td>
<td>Community Action Coalition</td>
</tr>
<tr>
<td>CDC</td>
<td>Centers for Disease Control</td>
</tr>
<tr>
<td>CME</td>
<td>Continuing Medical Education (credits)</td>
</tr>
<tr>
<td>CPS</td>
<td>Child Protective Services</td>
</tr>
<tr>
<td>CPT</td>
<td>Certified Physical Therapy</td>
</tr>
<tr>
<td>CSHCN</td>
<td>Children with Special Health Care Needs</td>
</tr>
<tr>
<td>CYSHCN</td>
<td>Children/Youth with Special Health Care Needs</td>
</tr>
<tr>
<td>CTED</td>
<td>(Department of) Community, Trade and Economic Development (a state agency)</td>
</tr>
<tr>
<td>CV</td>
<td>Children’s Village (in Yakima – Yakima Valley Memorial Hospital)</td>
</tr>
<tr>
<td>DD</td>
<td>Developmentally Disabled, Developmental Disabilities</td>
</tr>
<tr>
<td>DDD</td>
<td>Division of Developmental Disabilities (within DSHS)</td>
</tr>
<tr>
<td>DOH</td>
<td>Department of Health (state level)</td>
</tr>
<tr>
<td>DSHS</td>
<td>Department of Social and Health Services</td>
</tr>
<tr>
<td>DVR</td>
<td>Division Vocational Rehabilitation (within DSHS)</td>
</tr>
<tr>
<td>Dx</td>
<td>Diagnosis</td>
</tr>
<tr>
<td>EI</td>
<td>Early Intervention</td>
</tr>
</tbody>
</table>
### Acronyms

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>EIBI</td>
<td>Early Intensive Behavioral Intervention</td>
</tr>
<tr>
<td>EPSDT</td>
<td>The Early Periodic Screening, Diagnosis, and Treatment (EPSDT) Program is the child health component of Medicaid.</td>
</tr>
<tr>
<td>ERISA</td>
<td>Employee Retirement Income Security Act</td>
</tr>
<tr>
<td>ESD</td>
<td>Educational Service District</td>
</tr>
<tr>
<td>FBAs</td>
<td>Functional Behavioral Assessments</td>
</tr>
<tr>
<td>FEAT</td>
<td>Families for Early Autism Treatment</td>
</tr>
<tr>
<td>FRC</td>
<td>Family Resource Coordinator</td>
</tr>
<tr>
<td>FTE</td>
<td>Full Time Employee</td>
</tr>
<tr>
<td>GI</td>
<td>Gastrointestinal</td>
</tr>
<tr>
<td>HCBS</td>
<td>Home and Community Based Services</td>
</tr>
<tr>
<td>HRSA</td>
<td>Health Resources and Services Administration</td>
</tr>
<tr>
<td>ID</td>
<td>Identification</td>
</tr>
<tr>
<td>IDEA</td>
<td>Individuals with Disabilities Education Act</td>
</tr>
<tr>
<td>IECC</td>
<td>Infant and Early Childhood Conference</td>
</tr>
<tr>
<td>IEP</td>
<td>Individual Education Plan</td>
</tr>
<tr>
<td>IFSP</td>
<td>Individual Family Service Plan</td>
</tr>
<tr>
<td>ITEIP</td>
<td>Infant Toddler Early Intervention Program</td>
</tr>
<tr>
<td>LHJ</td>
<td>Local Health Jurisdiction</td>
</tr>
<tr>
<td>MCH</td>
<td>Maternal and Child Health</td>
</tr>
<tr>
<td>MCHAT</td>
<td>Modified Checklist for Autism in Toddlers</td>
</tr>
<tr>
<td>NAC</td>
<td>Northwest Autism Center</td>
</tr>
<tr>
<td>NATTAP</td>
<td>Network of Autism Training and Technical Assistance Programs</td>
</tr>
<tr>
<td>NDT</td>
<td>Neurodevelopmental Therapy</td>
</tr>
<tr>
<td>NIH</td>
<td>National Institute of Health</td>
</tr>
<tr>
<td>OSPI</td>
<td>Office of the Superintendent of Public Instruction</td>
</tr>
<tr>
<td>OT</td>
<td>Occupational Therapy</td>
</tr>
<tr>
<td>PCP</td>
<td>Primary Care Provider</td>
</tr>
<tr>
<td>PDD.NOS</td>
<td>Pervasive Developmental Disorder, Not Otherwise Specified</td>
</tr>
<tr>
<td>PRS</td>
<td>Primary Referral Source</td>
</tr>
<tr>
<td>PT</td>
<td>Physical Therapy</td>
</tr>
<tr>
<td>RFP</td>
<td>Request Funds Proposal</td>
</tr>
<tr>
<td>RTN</td>
<td>Regional Training Networks</td>
</tr>
<tr>
<td>SB</td>
<td>Senate Bill</td>
</tr>
<tr>
<td>SEIU</td>
<td>Service Employees International Union</td>
</tr>
<tr>
<td>Abbreviation</td>
<td>Description</td>
</tr>
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</tr>
<tr>
<td>SICC</td>
<td>State Interagency Coordinating Council</td>
</tr>
<tr>
<td>SLP</td>
<td>Speech/Language Therapy</td>
</tr>
<tr>
<td>TOSA</td>
<td>Teachers on Special Assignment</td>
</tr>
<tr>
<td>TRACE</td>
<td>Tracking, Referral, and Assessment Center for Excellence</td>
</tr>
<tr>
<td>TVW</td>
<td>Washington State public affairs TV network</td>
</tr>
<tr>
<td>Tx</td>
<td>Treatments</td>
</tr>
<tr>
<td>UCP</td>
<td>United Cerebral Palsy</td>
</tr>
<tr>
<td>UW</td>
<td>University of Washington</td>
</tr>
<tr>
<td>WAC</td>
<td>Washington Administrative Code</td>
</tr>
<tr>
<td>WAMI</td>
<td>A cooperative regional network for medical students of Washington, Alaska, Montana, Idaho and the University of Washington</td>
</tr>
</tbody>
</table>
Bibliography


