

**Caring for
Washington
Individuals
With Autism Task Force**

Report to the Governor and the Legislature

December 2006

Caring for Washington Individuals With Autism

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Caring for Washington Individuals With Autism

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Executive Summary

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 (IT), 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.

Conclusion

The urgent need to move forward with systems level change convinces us that the recommendations herein are most suitable for the work at hand. The Caring for Washington Individuals with Autism Task Force is grateful for the opportunity to provide these recommendations to the Governor and legislators of our state.

Final Report

Introduction

Mandates of Senate Bill 5311

In 2005, Governor Gregoire signed into law Senate Bill 5311, creating the Caring for Washington Individuals with Autism Task Force. The task force was mandated to:

- 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.
- Review available literature and consult with experts to gain an understanding of the causes of the disorder and its incidence in Washington.
- Assess the availability of services currently provided for early screening, diagnosis and treatment of the disorder.
- Assess the availability of services to assist families of individuals with autism.
- Review the effectiveness of programs and services provided to individuals with autism and their families.
- Review other issues and concerns that the task force believes would be helpful in arriving at sound policy recommendations.
- Complete its review and submit its recommendations to the appropriate policy and fiscal committees of

How to Use This Report

This recommendations report is designed to give readers an overview of the key recommendations made by the Caring for Washington Individuals with Autism Task Force. The Emerging Themes of Concern (Appendix 1) lists additional ideas generated during Task Force discussions. Task force discussions included consideration of reviewed, evidence-based research, testimony heard from expert panels, and public input. We encourage use of the Emerging Themes of Concern document as a starting point for future strategic planning. The bibliography gives an overview of information gathered and reviewed.

the legislature and the Governor by December 1, 2006.

The task force, during the course of 10 months, gathered and reviewed literature and consulted with experts including parents, professionals, and individuals with Autism Spectrum Disorder (ASD). The task force identified best practices and models in our state that have been developed to serve individuals with ASD. Significant barriers continue to prevent best practices and models from being effectively used. The most serious barriers are:

- Lack of access to early screening.
- Lack of understanding about the needs of adults with ASD and individuals with Asperger's Syndrome.
- Lack of ongoing ASD training for providers, educators and parents.
- Inadequate links between screening, diagnosis and appropriate intervention (including therapies and comprehensive health care).
- Inadequate parent and family supports across the lifespan.
- Inadequate culturally competent interventions and services for families from diverse cultural and geographic communities.
- Inadequate financing strategies for enabling individuals with ASD to access appropriate care throughout their lives.

The work of the task force was guided by the following priorities:

- Obtain information from a broad group of individuals, agencies, and organizations including

individuals with ASD, parents, educators, physicians, therapists, other health care providers and researchers who serve people with ASD, to gain a comprehensive picture of available services and gaps.

- Identify peer reviewed literature recommended by the Autism Task Force and others to use as key sources of information for recommendations.
- Identify best practice standards.
- Place emphasis on using evidence-based criteria for recommendations.
- Build a statewide system for early screening, diagnosis and intervention.
- Meet the information and training needs of parents, teachers, clinicians and professionals concerned about ASD.
- Examine needs and resources in the educational system where many of the services are provided.
- Find ways to build community capacity to support individuals with ASD and their families.
- Focus on full lifespan of people with ASD.
- Identify where more funding is needed.

Understanding of Autism at Community Level

ASD is a spectrum disorder. This means that individuals with this disorder vary in how they are affected and how severely they are affected. There is also wide variation in how individuals with ASD respond to intervention. Although we know that all individuals with ASD benefit from intervention, it is impossible to predict who will

Almost everyone who presented to the Task Force—parents of individuals with ASD, individuals with ASD, and professionals across disciplines—are concerned about the lack of knowledge and understanding about ASD that exists in the community. Many parents related stories about people in the community who were intolerant of behaviors demonstrated by their children with ASD. Some people assume these behaviors were due to “bad and over-indulgent parenting.” Some adults with ASD described how difficult it is for them to maintain employment because of misunderstandings colleagues and supervisors have about their behavior. Professionals who work with students with ASD and vocational counselors who work with adults with ASD described colleagues in schools and workplaces who are resistant to needed accommodations. Their colleagues lack an understanding of the complexities of needs individuals with ASD have. Clearly, there is a need for education for the citizens of our state about ASD and what individuals with ASD need to be successful. This is starting to take place with a series of Public Service Announcements that are being funded by the Centers for Disease Control and Prevention, and Autism Speaks. More education is needed and this education is the first step toward the full inclusion of people with ASD into our society.

benefit the most from what types of intervention. This variation in the severity of the disorder and individual's response to intervention mandates that decisions about the effectiveness of any intervention for ASD must be based on data.

Individuals with ASD should be included in every aspect of our communities. As young children, individuals with ASD should be included in child care programs and community centers. When children reach school age, they should be included to the greatest extent possible in general education and extra curricular activities. As adolescents, individuals with ASD should be included in activities in their communities, in their schools, and in community colleges. As adults, individuals with ASD should be able to find satisfying work, a safe place to live, and a productive way to contribute to the community.

In the recommendations outlined in this report, much attention is given to training. These training activities include service providers across disciplines, family members (extending beyond parents to include grandparents, aunts and uncles, and siblings), individuals who are in decision making positions at schools, state agencies, and funding sources (e.g., Medicaid). This specialized training is essential to insure adequate programming for individuals with ASD. If, however, we want to go beyond adequacy of services and move toward the full inclusion of individuals with ASD, training must move outside of professionals and family members to include all members of our community.

Prevalence and Incidence

ASD affects as many as 1 in 166 children nationally.¹ In Washington the rate is similar, estimated to be

¹ Centers for Disease Control and Prevention, Fact Sheet, CDC Autism Research, May 4, 2006.

between 2-6 children per 1000. Significant disparities exist based on race, ethnicity and economic status, and males are affected 3-4 times more often than females.² Populations of color are especially vulnerable to inadequate interventions due to system barriers leading to late diagnosis.³ Currently, Caucasian children are on average seen by a physician four times before diagnosis is made, while African American children must be seen on average 13 times before diagnosis.⁴

Understanding ASD prevalence (number of current cases) and incidence (number of new cases during a specific period) is a complex process. Accurate parent-reported diagnosis of autism, the measure used in the national surveys, is dependent on access to health care services and communication of the diagnosis to the parent. In addition, studies that use cases determined from medical and other records may overlook children with a mild form of ASD. Because of these limitations, we do not know the exact prevalence of ASD.

Steps are being taken to increase Washington's ability to track ASD.⁵ Current state estimates are based on national and state survey data and information gathered through the Office of Superintendent of Public Instruction (OSPI).⁶ Washington Administrative Code (WAC) 246-101 specifies a list of health care conditions, called notifiable conditions, that must be reported to public health authorities. That list was expanded in 2004 to include Autism Spectrum Disorders. The Department of Health has been working with the

2 Autism Task Force Presentation, November 2005.

3 A number of barriers may underlie this problem. Panelists addressed cultural barriers that kept them from asking for services.

4 Mandell et al, JAACP, 2002.

5 See Appendix 5. Note Washington added ASD to its list of Notifiable Conditions in 2004.

6 Office of Superintendent of Public Instruction IDEA Part B Child Count Report, December 2005. Note OSPI reports to the federal Department of Education the number of students receiving special education services.

University of Washington, OSPI and other partners to develop a reporting system.

Causes of ASD

Both genetic and environmental factors appear to play a role in causing autism. Five to 10 percent of autism cases are due to an identifiable medical disorder with a known inheritance pattern, including Fragile X syndrome, untreated phenylketonuria (PKU), tuberous sclerosis and neurofibromatosis. Fragile X syndrome accounts for about 8 percent of the cases of autism. Twin studies show evidence of a strong genetic component to autism. Family studies also indicate the heritability of autism. The likelihood of having a second child with autism is estimated at 4.5 percent—45-90 times greater than the general population risk.

Research indicates that autism is most likely the result of multiple genes (5-10 or more). Recent studies suggest that autism susceptibility genes are very likely located on chromosome 7. Several genes appear to be involved, and different genes appear to be causing the disorder in boys and girls.

It is likely that these genes interact with environmental factors to predispose a child to autism. Although specific environmental factors that play a role in the majority of cases have yet to be identified, such factors might include viral infection, other infections, injury (trauma), diet and chemical toxics.⁷

Parents' concerns about their children's exposure to environmental toxics, including past exposure to mercury in the form of the preservative thimerosal in immunizations, have been taken seriously by the task force. Research on the effects of thimerosal on brain

⁷ Dawson, G. & Toth, K. (2006). Autism Spectrum Disorders. In D. Cicchetti & D. Cohen (Eds.), *Developmental Psychopathology*, second edition, volume three: Risk, disorder and adaptation.

development is being conducted at the University of Washington, and the primary author of that research, Thomas Burbacher, spoke to the Task Force.

It is important to note that the available evidence does not support the notion that thimerosal exposure causes ASD, but due to parental and provider concerns, the American Academy of Pediatrics urged the removal of thimerosal from immunizations in 2000. The Washington Legislature passed SB 5305 in March 2006, prohibiting vaccinating pregnant women and children with mercury-containing vaccines. Thimerosal-free vaccines are now available for all routine childhood immunizations. SB 5305 recognizes the important role immunization plays in protecting the public from disease and the need for public trust.

There is much we still need to know about causation, and ongoing scientific research must continue.

Availability of Services for Treatment

The task force found that there is a great need for improved early detection, access to early intervention, professional training to build capacity for services in the community, and access to life long, multi-disciplinary services in a comprehensive health care model.

Improved Early Detection

Autism can be detected by 18 months. However, the average age of diagnosis is much later, between six and seven years of age.⁸ Significant disparities exist based on race and ethnicity: African American children are diagnosed one and a half years later than Caucasian

⁸ Mandell, et al. Journal of American Academy of Child and Adolescent Psychiatry, 2002.

children, and require three times the number of visits to get a diagnosis.⁹

Without early screening, children with ASD do not receive the substantial help they need. The consequences of this are serious: many children remain mute their entire lives, 75 percent are mentally retarded and need life long intensive care, 41 percent require psychiatric hospitalization, and very few develop meaningful friendships or marry. With appropriate assistance, outcomes are significantly improved for some children. A substantial proportion of children are able to attend regular education classes; gain communication skills, including verbal language; participate in community life, find employment, and live independently with supports. IQ scores increase on average 1.5 to 2 standard deviations. It is known that children with higher IQs are likely to respond better and make more progress, and it appears that gains may be stable into adolescence, especially with ongoing assistance.

The key to early identification is working closely with the medical community. Pediatricians and family practice doctors are in an ideal position to identify and refer children with developmental delays. Most children obtain health care on an ongoing basis from birth, giving physicians an opportunity to develop on-going, trusting, confidential relationships with families. Many parents consider their physician to be a trusted advisor on the health and development of their child. It is essential for physicians to be able to identify young children at risk for ASD, refer the children for appropriate assessment, and assist the family with information and resources.

Screening tools are available to assist in identifying children with ASD as early as 18 months. These tools include the Checklist for Autism in Toddlers (M-CHAT);

⁹ Ibid.

First Signs; and Autism Alert. Medical providers need more training and incentives for using an early screening tool.

Access to Early Intervention

Benefits of early intervention should be made available to all children with ASD from a young age. National Research Council recommendations for early intervention stress that services should begin as soon as ASD is suspected. Services should include a minimum of 25 hours per week, 12 months per year of appropriate interventions. Depending upon the age and needs of the child and the family, a systematically planned, developmentally appropriate educational plan should be developed that works towards identified objectives.

Common elements of effective early intervention programs include:

1. comprehensive curriculum, addressing core domains of imitation, language, toy play, and social interaction;
2. sensitivity to normal developmental sequences,
3. highly supportive teaching strategies based on applied behavioral analytic procedures,
4. behavioral strategies for reducing interfering behaviors,
5. involvement of parents as partners,
6. gradual, careful transition from a highly supportive environment (usually one on one) to a less structured environment (small group),
7. highly trained staff,

8. supervisory and review mechanisms,
9. intensive, i.e., at least 25 hours per week of structured intervention for at least two years (per National Research Council recommendations), and
10. onset of intervention by two years of age.

Professional Training to Build Capacity for Services in the Community

Meeting the needs of individuals with ASD is a complex undertaking. Having well trained professionals and well informed families and caregivers is a prerequisite to meeting those needs. On-going training for professionals (across multiple disciplines) and paraprofessionals working with individuals with ASD is needed. ASD training should be tailored to address the distinct differences and responsibilities of each professional group. Physicians and other health care providers, educators, childcare providers, parents, first responders, and emergency preparedness planners must all receive appropriate training.

These training programs must be on-going, culturally effective, and provided in different languages. Training activities should be provided through the regional autism centers of excellence described in this report.

Access to Life-long, Multi-disciplinary Services in a Comprehensive Health Care Model

Transitions (for example, from early intervention programs to elementary school or high school to adult programs) are especially vulnerable periods. A proactive approach prevents serious problems, avoids costly care (for instance, a full time aide or psychiatric hospitalization) and offers hope for a productive, satisfying life for all individuals. Ongoing services

needed by children in grade school through adolescence include school services that are sensitive to the needs of children with ASD; physician related services such as pharmacological treatment for anxiety and medical conditions such as seizures; social/vocational training; and periodic assessment and counseling to provide appropriate tools for handling new behavioral challenges and emotional issues.

Treatment across all ages should be individualized and multi-disciplinary, and should include: medical needs (metabolic/genetic conditions (10-20 percent of population), seizures (25 percent of population), sleep disorders, gastrointestinal problems, allergies, co-morbid psychiatric conditions, psychosocial needs, educational needs, speech and language services, and occupational therapy. Multi-disciplinary care includes psychologists, educators, applied behavior analysts, speech/language pathologists, occupational therapists, and medical professionals.

Effect on Families

Families with children with ASD are particularly vulnerable to stress and are often isolated and lacking support. ASD is a “24/7” disorder that affects individuals 365 days a year. Public schools run 180 days a year, six hours a day; many other public services may occur once a week or even less frequently. 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.¹⁰

According to the U.S. Census Bureau (2000), 47 percent of first marriages and 57 percent of all marriages end in divorce. Families with a child with ASD or

¹⁰ Insel, T., Director NIMH, 2005 referenced in Power Point presented by Dawson, G., Autism: the Public Health Challenge, January 2006.

other disabilities report even higher levels of marital distress.¹¹ Financial burdens can be extreme, with some parents leaving their job to care for their child with ASD, decreasing the family's income even as health care expenses increase. Siblings commonly contend with decreased attention and support from parents while parents invest considerable time and energy getting a diagnosis and treatment for the child with ASD. Families may find themselves isolated from friends, family, and community because the child's behaviors are so unpredictable.¹² Natural supports offered by family and friends are less available as a result. Increased stress to the family frequently results in decreased quality of life, and economic instability.

Adults with high functioning Autism and Asperger's Syndrome who spoke to the Task Force identified how difficult it is to obtain and maintain employment. Other panelists described how, within their culture, asking for help is seen as a weakness, which makes the experience even more isolating. The stigma of disability is still a barrier for some families.

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." Many families who spoke to the Task Force cited Parent to Parent, Fathers Network, sibling support, and similar programs as critical to their sense of well being and connectedness. Family resilience is strengthened through culturally and linguistically effective family supports and social connection with other families who experience ASD.

¹¹ Seligman, M & Darling, R., *Ordinary Families, Special Children: Systems Approach to Childhood Disability*, Second Edition, 2006

¹² <http://www.autism-society.org/site/PageServer?pagename+LivingwithAutism>

Funding

Meeting the needs of individuals with ASD is a complex and expensive undertaking. The task force recommendations will require new funding. The task force encourages the legislature to explore new funding sources, including accessing Medicaid funding, blending funding sources across existing programs, and fully funding basic and special education. The recommendations in this report, including the regional autism centers of excellence and optimal treatment goals for individuals with ASD, will require new funding.

Evidence-Based Practices

Using research to inform practice in the fields of medicine, education, allied health, and other fields related to behavioral health is becoming standard practice. When providing services to individuals with ASD it is essential to look at the research literature for what has been proven to be effective and to continue to evaluate services at the individual level. One of the challenges of working with individuals with ASD is that there is such wide variation in how the disorder presents and how individuals respond to intervention. Therefore, it is essential that we use existing evidence to make initial choices about interventions, and that we collect ongoing data about how the individual responds to the intervention to determine its effectiveness.

Life Long Services and Supports

ASD is a lifelong disability. Despite very good advances in intervention and the success experienced by many individuals with ASD, most people with ASD will need some level of specialized supports and services throughout their lifetime. These services need to be consistent, comprehensive, high quality, publicly funded, and of necessary intensity to facilitate appropriate outcomes. Although this list is not comprehensive, it is

necessary to provide services across the following areas: Early Screening, Diagnosis, and Referral to Intervention; Early Learning and Care; School Age; Secondary Education; Adult Vocational Services; Long Term Care.

Residential Options

Issues around residential services are also a concern for individuals with ASD. These issues fall into three main categories. First, although it is always preferable for children to live with their parents, there are situations when challenging behavior or severe support needs make it impossible for children with ASD to remain at home. Currently there is a dearth of residential options for children with ASD in our state. Not only are there few options, there are even fewer high quality options that are publicly funded. Residential options for children and young adults with ASD, both short and long term, are necessary.

Second, it is a normal part of the life cycle in many western cultures for young adults to move out of their parents' home to live independently or with friends. Our state needs to provide residential options for young adults with ASD. These options need to include a continuum of options with varying supports that individuals can access.

Finally, individuals with ASD have normal life expectancy. Therefore, our state needs to provide options for adults with ASD throughout their lifetime. These options may include independent living, group homes, or more creative individualized options.

Consistency of Services Across the State

Task Force members were impressed with reports (and their own experiences) related to the difficulty many

individuals with ASD and their families have accessing high quality services. These difficulties are even more pronounced outside of the greater Seattle area, and for individuals and their families who are culturally and linguistically diverse. All individuals with ASD and their families should be able to access high quality, publicly funded services in their own communities with no waiting lists.

Essential Groundwork for Improving Autism Services

The Task Force identified four major areas where significant change must be made: Infrastructure (IN), Treatment (TT), Training (TG) and Funding (F). Some of the recommendations in this report will require long term systems changes. However, the Task Force believed the following recommendations are essential first steps in improving 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 of educators, physicians, therapists, and other professionals who work with people with ASD, thus increasing the capacity of Washington to provide ASD services at the regional and community level. Regional autism centers of excellence 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 State 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 Service 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 Service Guidelines for Individuals with ASD. The Task Force recommends that Washington's Autism Services Guidebook include information and resources from birth through the lifespan.

Next Steps: Implementation Planning

The task force recommends that the Governor continue it for an additional two years. Coordination and consistency are critical aspects of implementation planning. It is essential that Washington develop a cohesive, integrated system for addressing the recommendations delineated in this document. Such foresight will ensure excellence and efficiency in program development, and systematically reach every child, parent, and provider.

The purpose of the task force will necessarily be modified to reflect a change of focus toward implementation planning. In light of this, additional appointments to the task force should include:

- At least one individual with ASD to provide a regular presence for increasing our sensitivity and knowledge about the challenges of living with the disorder in our state.

- A representative of Washington Learns to provide additional input on education, which is a primary treatment for autism.
- An individual who can speak to transition, residency and employment, since individuals with ASD spend most of their life outside the education system.
- Representatives of regional hubs of autism activity in the state, representing Tacoma/Seattle, Spokane, Yakima, Tri-Cities, and Vancouver.
- Representatives from diverse racial and ethnic groups. While the Task Force strived to obtain diverse input through our panels and public input (including geographic, ethnic, racial, age, and other measures of diversity), we did not obtain as much racial/ethnic representation as we desired.

Recommendations

Infrastructure (IN)

Washington lacks the capacity to adequately provide ASD diagnostic services, coordinated care, and trained professionals who can serve individuals with ASD across the lifespan from birth through adulthood. Serious gaps occur at all levels and in all regions of the state. Many families simply cannot obtain timely diagnoses or services for their child.

Access to diagnostic services and therapies varies considerably. Families living in rural areas have to travel long distances to get a diagnosis and appropriate treatment. Even in urban areas where more services and ASD trained providers are available, waiting lists are long. Regional autism centers¹³ are designed to work in collaboration with universities to provide training opportunities for professionals such as medical students, therapists, educators, and others who work with individuals with ASD. The training aspect of regional autism centers serves to increase capacity at the regional level. This enables families to more easily access diagnostic services; comprehensive, coordinated, multidisciplinary health care services; appropriate evidence-based therapies such as speech, occupational therapy, effective education, and applied behavioral analysis (ABA); family and individual supports; and coordinated training initiatives for individuals with ASD. The centers are designed to work in partnership with existing service providers and supports, enhancing

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.

¹³ In Washington we currently have one regional autism center based at the University of Washington in Seattle/Tacoma; in Florida, the Florida Center for Autism and Related Disabilities has seven regional centers located near universities.

services already offered in the state. In addition to the existing University of Washington-based regional autism center in Seattle/Tacoma, the Task Force proposes siting autism centers of excellence in Vancouver, Tri-Cities, Yakima and Spokane to provide better geographic coverage and increase training capacity around the state.

IN-2

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

The medical needs of people with ASD are too often overlooked. In addition to the diagnostic and treatment needs associated with ASD, individuals need comprehensive care in a Medical Home. Currently, medical concerns including, but not limited to, gastrointestinal problems, nutritional and oral health concerns, and vision issues are too easily overlooked for patients who have ASD.

Medical Home¹⁴ is an approach to health care that is especially helpful to persons with disabilities, chronic conditions, and special health care needs such as ASD. For instance, in a Medical Home, an individual with ASD is seen by a health care provider or team of providers who understands how to provide and coordinate services such as ASD screening and referral, comprehensive medical care, vision and dental care, and mental/behavioral health services. See Appendix 5 for a checklist of items patients look for in a Medical Home.

IN-3

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

Individuals with ASD are being diagnosed late and not receiving the interventions needed; this is true for children and adults, and is especially problematic for populations of color. Once a person is diagnosed with ASD, it is important that an initial contact is made to establish a relationship and create momentum toward initiating actual services. Regional Autism Centers of

¹⁴ See www.medicalhome.org for more Medical Home information.

Excellence, as described in IN-1, could greatly improve the coordination and provision of care and facilitate timely referral and placement.

Surveillance of ASD in Washington has been problematic due to the evolving definition of ASD and the federal law precluding schools from sharing medical information about their students with public health entities. Washington Administrative Code (WAC) 246-101 specifies a list of health care conditions that must be reported to public health authorities. The list was expanded in 2004 to include ASDs on the list of Notifiable Conditions¹⁵ that must be reported by health care providers. The Department of Health is working with the University of Washington, Office of Superintendent of Public Instruction (OSPI) and other partners to develop a reporting system for surveillance. Services are currently tracked through OSPI's Autism Outreach Project. Momentum must be continued to increase and expand these activities.

Screening, diagnosis, & referral to intervention

Early screening and early intervention lead to significantly better outcomes. Unfortunately, many children with ASD are not being diagnosed early enough, nor receiving adequate intervention, because they are not being screened. Excellent screening tools are now available to screen children early and successfully. The Task Force identified tools that could be used much more widely,¹⁶ including Modified Checklist for Autism in Toddlers (M-CHAT), Autism Alarm and First Signs. The Task Force recommends

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.

¹⁵ Washington Administrative Code (WAC) 246-101

¹⁶ Examples of screening tools include First Signs and Autism Alarm, and M-CHAT.

that screening tools be made widely available and trainings be provided to ensure that pediatricians, family practitioners, nurses, family resource coordinators, child care providers, teachers, and parents are aware of the tools and use them.

Children who are identified as possibly having ASD must be referred to a center that provides a multidisciplinary evaluation or to a qualified professional.

TT-2

Screening, diagnosis, and referral to intervention for ASD and Asperger's Syndrome must take place across the lifespan.

Many individuals go through childhood, teen years and adulthood undiagnosed with ASD. When ASD is not properly diagnosed, individuals with high functioning autism or Asperger's Syndrome often experience social isolation, depression, unemployment and other problems that could be diagnosed and effectively treated. ASD screening training for family practitioners and other adult health providers is essential so that they can recognize the signs of ASD in teens and adults and properly refer patients for treatment.

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.

The literature and practice have shown that early, frequent, intense intervention is necessary to facilitate positive outcomes for children with ASD,¹⁷ yet many children do not receive adequate services birth to five. According to the National Research Council's volume, "Educating Children with Autism,"¹⁸ children with ASD need appropriate interventions 25 hours per week, 12 months per year. All children birth to five who are diagnosed with ASD or for whom the Individualized Family Support Plan/Individualized Education Plan (IFSP/IEP) team or qualified professional thinks a diagnosis of ASD is probable, must have access to

¹⁷ May Institute Research Developments, Issue 6, 2004

¹⁸ National Research Council, *Educating Children with Autism*, page 219

appropriate services. How services are designed and implemented depends upon how old the child is, where the child resides, and family choice. 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. Access to services should be made available even before a firm diagnosis is made.

Public School Services (Grades K-12 and Transition to Adulthood, Ages 18-21)

It can take a long time to get a diagnosis of ASD, given the lack of qualified diagnosticians and long waiting lists that currently exist. School children who may have ASD but have not yet received a firm diagnosis must be provided with appropriate services. The literature and practice have shown, as stated above, that early, frequent, intense intervention is necessary to facilitate positive outcomes.

All students with ASD must have access to appropriate¹⁹ services in the public school setting, for a minimum of 30 hours per week. This is true even when a firm diagnosis has not been obtained. Obtaining a provisional diagnosis is an important first step in accessing services. School psychologists can provide provisional diagnoses and refer out for a confirmatory diagnosis. While waiting for the confirmatory diagnosis, the student must start receiving appropriate services.

Educators, psychologists, and health care providers working together can ensure that children and youth receive diagnoses in a timely manner, and get the

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 a week of appropriate educational services.

¹⁹ Defined as individualized, multidisciplinary, culturally effective, evidence-based, legally required

services they need. Regional autism centers that provide training to health care providers, educators, psychologists and other professionals can develop increased capacity for diagnoses and treatment at the community level.

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.

Lack of ASD trained teachers and mentors in the school districts creates great difficulty in implementing ASD programs and strategies. A technical assistance person in each educational service district is critical to the success of educators and other professionals in providing positive, research based programs and supports within the schools. Resources, training, and knowledge levels vary greatly from school to school and district to district. 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.

Post-secondary Education & Employment (Transition and Adult Services)

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.

Because ASD is a lifelong disorder, adults with ASD must continue to receive appropriate, multidisciplinary support and services in order to maintain and further develop their capacity for employment. Optimally, adult services will be provided through use of Department of Social and Health Services (DSHS) programs, innovative partnerships between DSHS, regional autism centers, health care providers and other service providers.

Many students with ASD do not have an effective transition plan while still in high school. The transition plan, a component of the Individual Education Plan, is intended to assist the student in preparing for life after high school. Students must leave their entitled secondary education program with the knowledge, skills, supports or assistive technology to succeed in post-secondary education, vocational or technical school, supported employment, community living, recreation and leisure opportunities. Some individuals with ASD are able to be successful in higher education with support. Almost all can be successfully employed with appropriate supports.

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.

Not all students leaving high school have access to services that enable them to benefit from Washington's Working Age Adult policy,²⁰ which helps an individual, regardless of significance of disability, move along a pathway to employment. In order to be successful, the individual with ASD needs support that is provided by persons knowledgeable about ASD. Training will therefore be needed to prepare staff who work with adults with ASD.

TT-8

All Washington adults with ASD will be provided with appropriate, publicly funded services to enable them to benefit from the Working Age Adult Policy.

The Individuals with Disabilities Education Act (IDEA) requires transition services that include a coordinated set of activities to prepare students for leaving high school. The services include a results-oriented process that focuses on improving the academic and functional achievement of the student. This facilitates the student's movement from school to post-school activities, including postsecondary education, vocational education, integrated employment, continuing and

²⁰ For information on Washington Working Age Adult policy, go to: http://www1.dshs.wa.gov/pdf/adsa/ddd/policies/policy4.11_07_04.pdf#search=%22ddd%20working%20age%20adult%20policy%22.

adult education, adult services, independent living or community participation.²¹

Community Family Supports

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.

Even though there are many excellent services available for individuals with ASD and their families, it can be very difficult for families and providers to access this information. In order to make it easier for families and providers to access existing resources and services, it is recommended that an Autism Services Guidebook will be developed and made available to the public. The Guidebook, similar to the Ohio Service Guidelines for Individuals with ASD,²² will cover the full range of ASD services available over the lifespan. It would be available online, in CD format, translated into other languages, and available in public libraries throughout Washington.

TT-10

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

Finding child care providers who are willing and knowledgeable about providing services to children with ASD is a difficult or impossible task for most parents. In order for parents to work, they must have child care available to them. Child care providers do not accept children over 12 years of age. Children with ASD however, are often unable to take care of themselves at that age. In a 2006 Maryland study, 66 percent of children needing child care had special needs; 15 percent had an ASD diagnosis.²³ Childcare providers must be given ASD training and technical support to enable them to create appropriate, positive environments for children and teens with ASD.

²¹ IDEA requires interagency agreements between agencies that provide services to children and youth including coordination of transitions services. IDEA does not relieve any participant agency from providing or paying for transient services that the agency would otherwise provide to students who met the eligibility criteria of that agency.(IDEA 300.43;33.24;33.154.)

²² <http://www.ddc.ohio.gov/Pub/ASDGuide.PDF>

²³ <http://www.mdchildcare.org/mdcfc/pdfs/trends.pdf>

Many Washington families lack around the clock services and supports, designed to help people with disabilities stay in their homes and communities. Consider what happens when school lets out for the day, and the child with ASD heads home. Parents must either find someone to provide child care or respite, or leave their job by mid-afternoon in order to provide care. Children with ASD need high levels of supervision and ongoing interventions between the time school gets out and bedtime. Child care can be difficult to find for a child with ASD. Parents need trained respite and child care providers, and adults with ASD need trained providers who can engage them in meaningful activities that foster independence and inclusion in the community.

Waiting lists for respite and personal care providers can be two years long. Providers frequently lack proper training to work with individuals with ASD, and also need increased training to provide services in a culturally effective manner. Families would benefit immensely from having access to a list of skilled providers who offer wrap-around services.

Sometimes the pressure of caring for an individual with ASD is especially intense. Family preservation services and strategies are needed to help families, including siblings, maintain their strength and resilience. Since each family is different, consumer-driven, family directed interventions are imperative to assist families in staying together. Family preservation services and strategies may include autism education, autism training, planning, in-home supports, environmental modifications and coordination of family support services (e.g. trained respite and personal care providers), advocacy for the family with human service agencies, encouragement and emotional support to parents and siblings. Currently, some family preservation services are provided thorough

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.

family support services of DSHS. More openings are needed.

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.

Residential Option/Long Term Care

Placing an individual, especially a child, in a state institution is not a preference for most parents, even when out-of-home placement is necessary. Other options have been available to families in the past; only a few exist now and they are too costly for most parents to access.²⁴ Efforts must be made to re-establish or create new programs that focus on out-of-home placement for children using the following criterion: the family is deeply and meaningfully involved in all aspects of the placement; training and supports are provided for the family. Adults need options that provide residential service with staff trained in ASD supports, limiting use of medically induced restraints.

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.

ASD is a complex disorder, with much new information about causation and treatment coming forward every year. Professionals working with individuals with ASD need high quality and ongoing professional training, whether in health care, school, employment, or post-secondary educational settings. Quality interventions rely on highly trained personnel who receive ongoing, updated training and support to do their job well. A coordinated training program will be delivered by leveraging already existing model programs and developing new ones, implementing train the trainer strategies coordinated through the regional centers, and building on existing successful models already developed in Washington.

²⁴ Voluntary Placement Program info is at <http://apps.leg.wa.gov/WAC/default.aspx?cite=388-826>

Medical students, interns, and practicing physicians, in particular pediatricians and family practitioners, are the frontline when it comes to early screening for ASD, diagnosis, and referral to treatment and family supports. Many medical students, interns, and physicians have not been provided with the tools and training they need to provide these services in a timely manner. A training curriculum and process specifically designed to meet the needs of physicians is necessary, and should be implemented in the state's medical schools and residency training programs.

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.

There is a great need to improve entry-level competency and provider competency in the educator and allied health and human service professions. Information and training on ASD must be included in all post-secondary education preparation programs. Education curriculum must include, but not be limited to, basic ASD training, plus the school district approach to educational service provision. The latter must include components of administration support (e.g. superintendents and principals), awareness of the practice of deliberate inclusion, improved provider competency, needs of families, legal issues, and other aspects of caring for an individual with ASD. Regional Autism Centers of Excellence, in collaboration with the Department of Social and Health Services (DSHS), the Department of Health (DOH), and OSPI should coordinate this training.

TG-3

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

First responders who are called to the scene of an emergency often do not understand the behavior or characteristics of a person with ASD. Without proper training, first responders, including law enforcement, can easily misinterpret the behavior of a person with ASD. This can lead to unfortunate, even disastrous results.

TG-4

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

Law enforcement personnel and other first responders must receive ASD training to develop awareness of the needs and behaviors of individuals with ASD.

The legislature unanimously passed SB 5473 requiring the Criminal Justice Training Commission (CJTC) to train officers on interacting with persons with a developmental disability or mental illness. The CJTC created an interactive training on CD which has been distributed to all law enforcement agencies in our state. It is used now as an in-house training. By expanding SB 5473 to encompass all first responders, an already existing training tool could be effectively used to educate more professionals who interact with individuals with ASD. The existing training is divided into sections with one specifically aimed at interaction with individuals with autism.

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.

Like many people with chronic health conditions and disabilities, persons with ASD are especially vulnerable during emergencies. Sensory issues and changes in routine may lead to behaviors that are self injurious or perceived as anti-social. Some individuals may become lost and unable to give basic information such as their name, address, or medical needs. The Washington State Department of Health can provide resources and technical assistance in emergency plan development to address the needs of vulnerable populations including people with ASD.

FUNDING (F)

F-1

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

Disparate sources of funding are currently used to provide financing for treatment of ASD, including but not limited to private insurance; Medicaid; Basic and Special Education; Infant Toddler Early Intervention Part C monies; Division of Developmental Disabilities; Adult and Aging, Mental Health, Division of Vocational

Rehabilitation; Department of Health (Maternal Child Health, Children with Special Health Care Needs Program); housing and residential services, and community non-profit organizations. Careful evaluation and modification of current Medicaid reimbursement rates and procedures is necessary. Mechanisms to improve both private and publicly financed health insurance programs must be explored, as well as options for blending and pooling funding, coordinating services and promoting cooperation among these various agencies, and reimbursing providers more adequately. Other states that have made progress in improving financing of coverage for ASD include Maryland, Pennsylvania, and Massachusetts.²⁵

Washington residents with ASD struggle due to wait-lists for services across major parts of the state, a dearth of services in some areas, and a critical need for professional training. Regional Autism Centers of Excellence can provide state-of-the-art coordinated clinical services for children birth to late adolescence, increase capacity for services in the community through training, and increase public awareness and education about autism through informational and outreach services. Statewide Regional Autism Centers of Excellence have been developed in Florida, which serve as a model for our state. In Washington, current funding of the University of Washington Autism Center in Seattle/Tacoma provides an opportunity to continue to develop increased access to similar resources in other parts of the state. Creating additional regional autism centers of excellence can be accomplished by implementing a statewide professional training program, leveraging financial and technical resources already

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).

²⁵ McKenna, P, state funding for intensive early intervention for children with autism; A review of successful strategies, University of Washington Autism Center, July 2003

existing, and approving state insurance coverage for early intervention.

F-3

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

Families have to go through much time and effort to have important, evidence-based, necessary therapies and devices approved for their children with ASD. Multi-disciplinary therapies and interventions for adults with ASD are even harder to obtain, and yet they are needed to support the individual with ASD in continuing to develop important life skills and remain a functioning, productive member of the community. Mental health services are a critical element of health care. Employer-based private health insurance plans are generally inadequate in terms of financing ASD services or mental health services, although in Washington a few such plans have recently been created as a result of employer interest and support. Many private insurance companies cover neurodevelopmental therapies only through age six, and ASD is often excluded from coverage because it is considered by insurance plans to be a non-medical condition that should be handled by the educational system.

F-4

Fund community-based organizations that provide culturally effective parent and family support and resource information to families of individuals with ASD.

Families need access to culturally effective family-centered resources, support, and information. Talking with other families continues to be a critical way to get information and support. Individuals with ASD and their siblings and other family members benefit immensely from community supports such as the Autism Society of Washington and its chapters, parent coalitions, Families for Early Autism Treatment (FEAT), Parent to Parent, Fathers Network, Ethnic Outreach Coordinators, cultural brokers, and grass roots autism and family support groups. Partnerships with parent and family support groups and involvement of families in decision making are key aspects of treatment and

comprehensive care in a Medical Home. Families have a degree of peer credibility with other families that is not matched by any other service partner, especially during the early days of diagnosis.

Washington lacks a Medicaid Waiver application for children and adults with ASD that broadens the scope of available services and develops mechanisms to improve the quality of care provided to individuals living with autism. The federal government allows states to request that Medicaid regulations be waived so that appropriate services can be provided to specific groups of Medicaid-eligible individuals. This waiver process can significantly increase the flexibility and creativity that states have to provide care.²⁶

Inadequate funding for regular education causes financial hardship for schools struggling to meet the needs of all their students. Children with ASD may spend their first twenty-one years in the education system, and often receive special education funds. Special education funds and safety net funds help with extra costs.

The Joint Legislative Audit and Review Committee (JLARC) report on Special Education Excess Costs has shown Washington is the only state in the nation using our current cost accounting method, which is very complex.²⁷ Improved financing policies and processes must be identified for funding both regular education and special education safety net funding.

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.

26 Maryland's Autism Waiver info is at: http://www.dhmm.state.md.us/mma/waiver_programs/html/Autism%20Waiver%20Fact%20Sheet.htm

27 State of Washington Joint Legislative Audit and Review Committee (JLARC) Special Education Excess Cost Accounting and Reporting Requirements, Report 06-3, Feb 16, 2006. <http://jlarc.leg.wa.gov>

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.

Washington has an inadequate number of providers who are trained to work with children and adults with ASD. We must increase the number of available providers and increase community capacity. A student loan forgiveness program is one way Washington can attract professionals to our state. Regional Autism Centers of Excellence and community clinics would be ideal places to provide training for students and professional positions for new graduates, who would be attracted to our state through the student loan forgiveness program.

F-8

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

Creation of an Autism Awareness license plate will provide proceeds that can be used to promote programs benefiting individuals with ASD. These funds could be dedicated to the creation and distribution of the ASD Service Guidelines book described in recommendation TT-11. Washington's license plate program requires that legislation be passed approving a specific license plate designation. The proceeds from the sale of license plates may be designated for a specific purpose.

F-9

Create tax incentives for Washington's employers to provide meaningful employment opportunities for individuals with ASD.

Individuals with ASD have particular attributes conducive to employment, but also confront unique obstacles in the workplace. The willingness of employers to make reasonable accommodations for particular concerns (sensitivity to noise, an inordinate reaction to the disruption of routine, environmental change, etc.) is frequently necessary. Providing tax incentives for employers willing to make the necessary accommodations and providing employment opportunities for individuals with ASD is one way to increase the number of opportunities available to individuals with ASD, enabling them to be contributing, tax paying members of society.

Appendices

Appendix 1

Caring for Washington Individuals with Autism Task Force

Emerging Themes of Concern

This document contains background ideas generated at the many meetings of the Autism Task Force. It provides a rich overview of key concerns, ideas and potential actions that have been articulated by the task force in the course of its exploration of services available, gaps in services, and priority areas of concern.

Several themes emerged. Those themes were collapsed into ten global themes of concern:

- Infrastructure
- Early Screening, Diagnosis, and Referral to Intervention
- Comprehensive Health Services and Coverage, including Mental Health, Dental, Health Disparities—Medical Home Approach
- Public School Education/Placement/Consistency
- Transition, Employment, Residential Options and Long Term Care
- Community Supports, Family Support/Inclusion/Respite/Understanding of Autism at Community Level
- Long Term Care
- Evidence-Based Trustworthy Information
- Funding
- Assessing Effectiveness of Programs and Services

From these ten global themes of concern, the Task Force created four final recommendation categories: Infrastructure, Treatment, Training and Funding.

Infrastructure

- » Develop and/or support Autism Regional Centers of Excellence to improve the system. One of their tasks is to develop regional multi-tiered levels of training. Through regional centers, we will achieve more case coordination/management. Incorporate a coordinator like the FRC (Family Resources Coordinator) but who addresses issues across lifespan, not just early childhood.
- » One entity should be established to look at the whole system (recommend that regional centers are funded and that there is an advisory board made up of people who are directors of the regional centers [or current ATF] and consumers who monitor program effectiveness).
- » Wrap around services should be available year round and outside of the school setting.
- » Deliver services within a Medical Home. Physicians will be empowered to adopt the Medical Home concept in providing care to children affected with ASD.
- » Tie in the other systems that families are involved in: not just medical or school, but DSHS, neurodevelopmental centers, other systems.
- » Provide support for interagency coordination and collaboration.
- » Use the Medical Home approach towards care coordination. Incorporate Medical Home strategies.
- » The need for care coordination will still be there after someone graduates from school.

- » Tie in the other systems that parents are involved in: DSHS/schools/etc.

Early Screening, Diagnosis, and Referral to Intervention

- » All children will be screened for autism before the age of three (goal: 18 months).
- » All providers in child find positions will be knowledgeable in timely identification of children at risk for an ASD diagnosis.
- » All children identified at risk for an ASD diagnosis will be immediately referred for further evaluation and intervention services (simultaneously).
- » All children identified, diagnosed, and/or referred will be monitored for follow-up.
- » Process for identification and (referral for) diagnosis and intervention services in the early intervention and public education systems will reflect best practice guidelines (see “Educating Children with Autism” from the National Research Council). Implementation will be consistent across schools and across districts.
- » Process for identification, diagnosis, and referral in the health care system will reflect best practice guidelines.
- » Local, regularly occurring trainings in identification, diagnosis and referral for ASD will be available to health care providers and all those in child find positions/occupations.
- » Screening tools include Autism Alarm, First Signs and AAP’s recently revised guidelines, M-CHAT screening tool.

Treatment

- » Resources and tools for identification, diagnosis and referral will be made available to primary care providers (including appropriate areas in hospitals and clinics) and all those in child find positions (day cares, ancillary service providers, education system, ITN, DDD, etc.).
- » Statewide database will be developed for assessing prevalence and incidence of ASD.
- » Data regarding treatment, interventions, and outcomes will be collected for assessing effectiveness and possible profiling (strive to answer “what works and for whom”).
- » A plan for improving public awareness will be adopted and implemented/or supported if already happening through other organizations. Suggest collaboration with CDC’s public awareness campaign: Learn the Signs Act Early.
- » Training in the importance and method of early identification, diagnosis, and referral will be made available through courses for related services in higher education (special ed, general ed, ancillary services, psychology, etc.) and medical residency (family practice, pediatrics, psychiatry, etc.) programs.
- » Need a systematic plan for evaluating short and long-term effectiveness of items implemented (i.e., did timely identification and diagnosis improve? Are families satisfied with system of referral? Are providers reporting knowledge of screening tools and local resources?) This will require baseline data, and ongoing data collection.

Comprehensive Health Services and Coverage, including Mental Health, Dental, Health Disparities

Medical Home Approach

- » Provide Medical Homes for all individuals with ASD.
- » Make sure kids are getting high quality medical/dental services.
- » Make sure physicians talk to teachers, parents, etc.
- » Incorporate cultural competency in the physician patient/family relationship.
- » Address serious health disparities in persons of color.
- » Address the insurance gap.
- » Address the shortage of professionals.
- » **Consistency:** use a consistent process throughout the state to determine appropriate medical intervention programs for each individual.
- » Create guide book.
- » Ask what would promote improvements in health? The outcome we are looking for is that no disparity will exist. We have much work to do around multi-cultural medicine. We need a plan sensitive to such issues as ethnic diversity, rural location, and foster care status (and any other issues impacting standard accessibility) in providing the above to all children to be developed and implemented.
- » **Coordination of education and medical teams:** The education system and medical providers need to work together in developing an individualized

treatment plan for children with ASD. For example, most pediatrician panelists for the ATF said they work with individual children, not school systems per se, to implement an individualized treatment plan. Coordinated education and medical care must be an integral part of the implementation of an individualized treatment plan.

- » **Health care and medication:** Health care for individuals with ASD is vital. Unfortunately, the use of medications, or overuse of medications such as psychotropic and anti-psychotic drugs are prevalent in the medical treatment of ASD. Health care providers need to recognize when cognitive/behavioral approaches can be used in lieu of medications or as a complement to medications.
- » **Insurance:** There are health care disparities across Washington State for all disabilities. The task force was disturbed by data that shows great disparities related to diagnosing and treating ASD. Lack of insurance coverage for treatment of autism, along with a Washington state law that permits individual health insurance plans to exclude services for individuals with ASD, are serious barriers. Families need to focus on the care of their child and not the stress of finding services.
- » **Mental health/other health services:** Access to other health services such as dental and mental health services and mental health counselors are being lost or cut. With the high rate of depression for individuals with ASD, many mental health providers and educators should (but do not) have the training to treat them. Individuals go without treatment and end up taking their lives. The ATF recognizes the role of the primary care provider as well as specialists in many different disciplines of medical, psychological medicine and allied

health professionals. The ATF recommends that Washington State will have trained medical, psychological and allied health providers in the field of ASD to provide appropriate services to families and individuals with autism spectrum disorders.

- » **Early diagnostic services:** The availability of prompt services and limited waiting times, especially for early intervention services and diagnostic procedures. (See Early Screening, Diagnosis and Referral to Intervention section of this document.)
- » **Co-morbidity:** Currently there are too few resources for addressing co-morbidity and no standards of care, especially for co-occurring conditions. Medical and mental health providers will receive the training and understanding of co-morbid conditions with Autism through training and standards of competency.
- » Not enough understanding of Asperger's Syndrome; children with Asperger's are grossly underserved.
- » **Shortage of professionals:** Access to professionals is lacking and there is a shortage of trained pediatric sub-specialists. Important to make a diagnosis early in a child's life and include an evaluation of sleep behaviors. (Possible medical school incentives for Developmental Pediatricians?)
- » **Standards/methodologies:** Use evidence-based methodologies for diagnosis and treatment. Intense, frequent, and direct methodologies, and professional best practice guidelines, have been developed. These are only the beginning and they are not yet standards for practice, just parameters.
- » **Better training on options:** There are bottlenecks in diagnosis, treatment, and provision of care.

Sometimes providers are hesitant to diagnose a problem they feel they can do nothing about. A lack of awareness about treatment options among primary care providers contributes to this. A provisional diagnosis model would permit treatment to begin before a final diagnosis is made.

- » **Culture and community access:** Recognize the child as part of a family and in context of culture, community and resources; focusing on the family; staff have quickly learned that there are many cultural barriers they were not even aware of. They have faced challenges in getting families to comply and follow through with a treatment plan. Other providers noted that language is a significant barrier. Attaining services related to ASD is difficult for any family, add any other factor such as socioeconomic, cultural, and language barriers and obtaining services becomes even more difficult. The medical home model incorporates cultural competencies. Use a primary care model that is based on the principle of a medical home. Use a care coordinator, preferably a mid-level practitioner trained to handle complex care. Autism Treatment Network—best practice approach for health professionals.
- » **Transitioning children to adulthood:** There is little support for transitioning from pediatric to adult care.

Public School Education/Placement/Consistency

Training

- » We need to encourage school districts to step up to the challenge. Recommend partnering with Early Learning agency and other state partners. ATF values the following:
 - » Consistency.

Consistent process throughout the state to determine appropriate educational programs for each individual.

» Funding for services.

All children for whom autism is suspected will receive a minimum of 25 hours per week of appropriate services (note—identify funding source).

» Transition.

Lifelong

» Inclusion.

Lifelong

» Educational standards needed across the state:

- Right now decisions (educational) are currently made at the local level.
- Focus on training.
- Educational staff don't have the baseline knowledge they need to begin training.
- Have an Autism Specialist in every school district who can provide technical assistance, consultation, and local training in each district.
- Develop support for educators by their district's administration to reduce staff turn-over and poor training.
- Multi-cultural, geographic and inclusion requirements.
- Training for all teachers, peer educators, and other affected staff working with children with disabilities specifically related to intentional inclusion techniques.
- Incorporate representatives from minority populations into decision-making processes.

- Cultural gaps exist because service providers do not look at the challenge from the point of view of parents and children.
- Break down geographic barriers.
- County coordination with clear follow through responsibilities and accountability.
- Use advocates for families who practice different cultures and speak different languages.
- Address the impact union practices have on job assignments and inappropriate staff assignments.

Training systems

- » Provide recognition and incentives to retain experienced staff.
- » School administrators should be trained and informed.
- » Use the K20 system to provide information to all ESDs.
- » Need equitable expertise available across the state.
- » Statewide recommendations should consider work that is already being conducted.
- » Need more special education teachers, especially those who are bilingual in English and Spanish.
- » Compensate beginning special education teachers for the additional time it takes to become a special education teacher.
- » Implement peer training programs.
- » Emphasize a successful transition to higher education.

- » Employ staff who can identify and make appropriate accommodations at all levels of education.
- » Increase educational opportunities at the university level and create more opportunities for specialists to learn: could generate more trained professionals.
- » We need Developmental Disability medicine added to medical school curriculum.
- » Offer teachers an “inclusive education” degree.
- » Legislature has provided increased funding in the past ten years for ‘high demand fields.’ It is still challenging to get people to go into those fields and to work in public services when the rewards are greater in private practice.
- » Pursue use of the Professional Development in Autism (PDA) approach.

Identification

- » Process for identification, referral for diagnosis, and provision of intervention services in the public education system will reflect best practice guidelines as outlined in “Educating Children with Autism” from the National Research Council. Implementation will be consistent across schools and across districts.
- » Guidelines will be developed and implemented to facilitate timely educational identification of students with autism, including defining a school-based professional training process on characteristics of autism spectrum disorders and outlining a school-based ASD screening process. Teams of staff members will be trained to provide a strong internal school resource. Members of “child

find” teams will be trained to identify the “red flags of autism spectrum disorders.”

- » Children identified at risk for an ASD diagnosis will be immediately referred for further evaluation and entry into intervention programs as soon as an autism spectrum diagnosis is seriously considered.
- » Process for identification and referral for diagnosis of autism spectrum disorders will include a formal multidisciplinary evaluation of social behavior; language and nonverbal communication; adaptive behavior; motor skills; atypical behaviors; and cognitive status by a team of professionals experienced with autism spectrum disorders. Implementation will be consistent across schools and districts.

Family Involvement

- » Families will be provided with materials and information specific to autism and educational approaches at the beginning of the assessment process. Parents will be directly involved and included as participating partners in development of the Individualized Education Plan (IEP) and Individual Family Support Plan (IFSP). Parents will be included in assessment of outcomes in order to provide consistency and continued progress across environments.

Education

- » Education of children birth through age eight will reflect best practice guidelines as determined by the National Research Council in “Educating Children with Autism.” Recommendations for programming will be based on the child’s individual needs which may include a minimum 25 hours/week, year-round instruction provision and components of direct

- instruction and inclusion with typically developing classmates.
- » Educational programs for all children with autism spectrum disorders will include family involvement; comprehensive assessment of skills and deficits; plan development; clearly defined goals and objectives; effective teaching strategies; assessment of the intervention; structuring the environment; applying functional behavior assessment to problem behavior; transition; opportunities with peers; and comprehensive team approaches.
 - » Intervention programs for students with ASD will include systematic instruction, functional objectives and meaningful activities, functional communication systems, effective motivational systems, and a system for behavior intervention.
 - » School districts will implement deliberate plans for improving inclusion at all grade levels, including opportunities for interaction with typically developing peers in both unstructured and planned interactions; instruction and support for students to maximize successful interactions; knowledge and support (peer training) for typically developing peers to facilitate and encourage meaningful interactions; and training and ongoing support provided to teachers and staff.
 - » Transition across grade levels or programs will be systematically addressed to prepare all individuals involved in the transition. Written transition plans will include clearly stated responsibilities and time lines for all individuals involved in the transition. A meeting will be conducted, either during the annual conference or at a separate transition planning meeting, to exchange information about effective instructional strategies; needed modifications and adaptations; positive behavior support strategies;

methods of communication; and inclusion with typically developing classmates.

Training for Educators

- » Training and professional development will be required in order to ensure that all general and special education teachers, paraeducators, principals, speech and language therapists, occupational therapists, psychologists, and all other school employees who have contact with children with autism are adequately prepared to make knowledgeable and appropriate decisions to facilitate delivery of a free appropriate public education.
- » All teachers working with students on the autism spectrum will have specialized training concerning best practices for children with autism spectrum disorders, including understanding of the core deficits of autism; competency in program development; classroom-based approaches to communication and social development; functional behavior assessment; educational and behavioral intervention through positive behavior support plans; data collection; and staff management skills.
- » Administration will support and encourage all personnel working with students with autism spectrum disorders to receive continuing and ongoing education at autism specific workshops and trainings.

Assessment of Progress

- » Criteria and standards will be developed for schools and districts to use as a guide in development of Individualized Education Plans (IEP) for students with autism spectrum disorders through continuation of the statewide Autism Outreach

Project and delivered through Regional Autism Consulting Cadres similar to the already established ESD 112 Regional Autism Consulting Cadre. Implementation will occur across schools and districts.

- » Criteria and standards will be developed to assess the development and implementation of an appropriate comprehensive educational approach within each school district for students with autism spectrum disorders, through the continuation of the statewide Autism Outreach Project and localized autism cadre development through ESD's across the state of Washington.
- » Criteria and standards will be developed for school districts to regularly assess staff effectiveness in program implementation and use of preferred methods in educating children with autism, through the continuation of the statewide Autism Outreach Project and localized autism cadre development through Educational Service Districts across the state of Washington.
- » School staff will have ongoing access to a professional consultant in autism, whose services will include site visits, input on program development, feedback on staff effectiveness and student progress, through the continuation of the statewide Autism Outreach Project and localized autism cadre development through ESDs across the state of Washington.

Transition, Employment, Residential Options and Long Term Care

- » Transition over the lifespan: multidisciplinary and individualized services are important for all ages.

- » Job and career options limited unnecessarily through lack of supports and inappropriate placements.
- » One panelist noted that it took concentrated work with a mental health therapist to develop self esteem after years of being told she was inadequate. Others noted that despite their efforts to find meaningful work, they repeatedly fail to find jobs or lose the jobs due to mismatch between their verbal communication disorders and the needs of the job, and this is very demoralizing.
- » Create a statewide standard and protocol for effective transition of individuals with autism from one service system to another. Transition for individuals with Autism throughout the lifespan should include:
 - Education.
 - Medical/Dental.
 - Employment/Supported Employment.
 - Department of Developmental Disabilities.
 - Department of Vocational Rehabilitation.
 - Residential/Assisted Living.
 - Respite/Personal Care.
 - Counselors.
- » Autism Spectrum Disorder expertise in transition should be present at regional, local and district levels for information on transition through the lifespan. These programs and services should not have waiting lists. Programs for transition will be based on best practice information and supports through the continuation of statewide autism leadership (AOP) and development of local training programs (similar to ESD112 Regional Autism Consulting Cadre, University of Washington Autism Center, Seattle and Tacoma, Washington Initiative

for Supported Employment, Aspergers Support Network, Center for Change in Transition, etc.).

- » Transition from school to post school activities should include a buildable portfolio based on the individual with ASD core deficits:
 - Communication.
 - Social/Emotional/Perspective Taking.
 - Focus on generalization and maintenance of skills.
 - Learning Style.
 - Executive Functioning/Organization/Problem Solving/Choice Making.
 - Understanding their Autism, self-advocacy, self-determination.
- » Transition activities should include the collaboration and blending of service resources well before the 21st birthday to support the expertise continuity in supporting an individual with Autism Spectrum Disorders; including schools, colleges, vocational programs, employment, supported employment providers, etc.
- » Supported Employment/Day Program service providers will have specialized training in best practice supports and strategies to support individuals with autism spectrum disorders at work and in the community. The providers and staff will have specialized training in the core deficits of autism; providing competency in employment environment structure/development, functional behavioral assessment, social/emotional, communication, educational and behavioral intervention (through positive behavior support plans), data collection, staff management skills, etc.
- » Supported Employment/Day Program providers and staff will envelop best practice information and

supports through the continuation of local autism support and resources such as Washington Initiative for Supported Employment Autism Project, Behavior as Communication and other resources.

- » Washington State University, colleges and vocational programs will have research-based standards for effective educational accommodations and modifications for an individual with autism who attends post secondary education. Staff for the Office of Disabilities within Washington State universities, colleges, and vocational programs will have training and competency skills with resources and access to training to support the needs of individuals with Autism Spectrum Disorders:
 - Career development.
 - Self-Disclosure of Autism Spectrum Disorder.
 - Accommodations and modifications for the class, professor, room mate, etc.
- » Autism Spectrum Disorder expertise in post-secondary education transition should be present at regional, local and district levels. These programs and services will not have waiting lists. The Office of Disabilities within Washington State University system will provide training in best practices supports for individuals with autism through the statewide leadership of the University of Washington Autism Center, Seattle and Tacoma and the Center for Human Development and Disabilities; Center for Change in Transition Services, and other partners.
- » Research-based standards for effective residential services (with necessary resources for training in interventions) for individuals of all ages who experience autism. Residential options for individuals with Autism Spectrums Disorders will

be based on the individuals' needs of support, such as:

- Companion Home based on evaluation and data from Autism Community Services Program.
 - Assisted Living Services.
 - Residential service providers will have specialized training in best practice supports and strategies. The providers and staff will have specialized training in the education of the core deficits of autism; providing competency in residential/home/environment development, functional behavioral assessment, social/emotional, communication, educational and behavioral intervention (through positive behavior support plans), data collection, staff management skills, etc.
 - Community Awareness of Autism.
 - Employers.
 - Recreation/Leisure Activities.
 - Retail Businesses.
 - Faith Based Organizations.
 - Law Enforcement (there is an interactive training already available).
- » Autism Awareness should be present at regional, local and district levels for information on Autism Spectrum Disorders. Programs that present Autism Awareness will envelop best practice information and training through the continuation of our statewide Autism Society of Washington (ASW), community chapters of ASW, Families for Effective Autism Treatment (FEAT), National Alliance for Autism Research (NAAR), Northwest Autism Center, UW Autism Centers (Seattle/Tacoma), and other partners.
- » Give employers incentives to hire people with ASD.

Community Supports/Family Support/Inclusion/Respite/Understanding of Autism at Community Level

- » Develop resource guidebook—similar to Ohio Service Guidelines for Individuals with Autism.
- » Respite is needed.
- » Wrap-around services (e.g. after school supportive recreation, employment or child care services, weekend and summer support) are needed.
- » Family and community outreach to all:
 - Ethnicities.
 - Local, regional, family support organizations (P2P/FN/others).
 - Build on existing models.
 - Have families tell law enforcement about their kids with ASD.
- » **Supports for Families:** Support for parents/families of children with autism spectrum disorders AND need to provide sibling support AND support parents by getting them information on autism and help them navigate the system. Parent to Parent and Fathers Network were identified by four of five parent panelists as having been an essential support to their family.
- » **Training and Information:** Training for child care providers, including autism information and information on what the family needs.
- » **Community Interaction:** Protect safety and independence of growing kids. Law enforcement interaction with individuals with autism is serious concern. Provide ways to increase inclusion of individual into society and community.

- » **Educational Support/Training:** Improve the capacity of school districts through teacher training and encouraging parents to educate themselves. Educators need to understand the needs of kids with ASD. Peer mentoring for kids is needed since there is often a lack of opportunity for social interaction for children with autism spectrum disorders.
- » **Cultural Support:** Reach out to diverse communities and families.
- » **Community Coordination/Support:** Each local community has to have a coordinator, someone to bring all the pieces together and know the resources in the community. There are not enough trained professionals to cover the need. Need vision setting regarding adopting the philosophy of a neighborhood school, designation of an autism specialist, and participation in an Autism Cadre. Use person-centered care with focus on family and family preservation. Use a large team of professionals who develop an individualized plan.
- » **Respite:** Explore ideas of local respite resources to give families a break; recreation/leisure resources and feeling of support. Provide trained Respite Care Providers for parents through respite care funding to be provided to families of children with autism spectrum disorders.

Long Term Recommendations

- » Most children with developmental disabilities including autism live with their families. A number of adults with developmental disabilities continue to live with their families.
- » Most children with developmental disabilities who live out of their family home are placed out

of home because of significant behavioral issues. Children may be voluntarily placed into out-of-home care if their family is unable to continue to provide the care that they need, but they don't want to give up their rights as parents (Voluntary Placement Program or VPP).

- » Out of home placement options include Intermediate Care Facilities for the Mentally Retarded (ICF/MR) (a placement option that may be an entitlement depending on whether the child or adult meets the admission criteria), child foster care, child group care or staffed residential homes for children. All community based out-of-home placement options for children are licensed through the Division of Licensed Resources (DLR) in the Children's Administration (CA), Department of Social and Health Services (DSHS). Depending on the age of the child, children that present significant behavioral challenges are usually supported in staffed residential settings.
- » Children with autism may present significant care issues to their caregivers. When families ask for out-of home placement, it is usually because they can no longer cope with the severe behavioral challenges their child presents. Sometimes those challenges include dangerous behaviors to parents and/or to other siblings in the family home.
- » School programs provide some support to families by engaging the child in learning and development activities for 4-6 hours on weekdays. When the child transitions from public school programs as a working age adult, no consistent support is available for the young adult to be employed. Support does exist in the form of personal care support but often the person's issues are behavioral in nature and support to do personal care tasks does not keep

her/him engaged in productive activity leaving the person to react behaviorally.

- » The best place for a child to be is at home. Family homes must be supported to be safe and healthy environments for everyone in them including parents, the child with disabilities and her/his brothers and sisters. An array of supports should be available to families with the expected outcome of a safe and healthy environment.
- » For those young people with families who are able to continue to support them after transition from public school, employment supports are necessary to ensure the person continues to be a productive member of her/his community.
- » For those young people that present severe and/or dangerous behavioral challenges to their families, out-of-home placement must be an option. The out-of-home placement should be cost effective and in the least restrictive setting with the proper support.

Long Term Care

Support to Families

- » Ready availability of respite with access to providers trained to support people with autism. For example, Autism Family Support Services provides a statewide current listing of skilled respite care providers. Providers should be paid according to the specific level of skills that are required to support the individual they are supporting.
- » Wraparound services should be available to families when periodic respite is insufficient to maintain the family unit. Funding should be available for family preservation services that would include

Long Term Care

education, training, planning, skilled in-home supports, environmental modifications, respite, personal care, needed support to parents and siblings, mental health and behavioral interventions. Professionals such as case managers, teachers, therapists, and family resource coordinators should have ready access to such services, and families and family advocates should be aware and informed of availability so that they may make requests.

- » Once the decision is made that out-of-home placement is required, families should have a variety of possible options that are age appropriate and offer skilled support people specifically trained to meet the needs of the individual served. Whatever option is chosen must be age-appropriate, provide sufficient support to meet the person's needs, provide the person as much opportunity to be independent as possible, be periodically evaluated, certified, and/or licensed.
- » Shared parenting options should be available to families of children. Providers should foster and encourage maintenance of family and friends relationships once the person has moved.

Evidence-Based Trustworthy Information

- » By law, school districts and insurance companies are required to provide services that are evidence-based. Task Force recommendations should be tied to evidence-based approaches.
- » Appropriately trained personnel are essential in order to implement evidence-based practices.
- » Regional centers will make available appropriate training for individuals, families and professionals at the community level.

- » Consistent process needed throughout the state to determine appropriate educational programs for each individual.
- » Washington has a new law regarding evidence-based decisions for Medicaid coverage.
- » Evidence-based information should be made accessible to the public and provide the basis for statewide programs. This information should be made available through the Autism Outreach Project and the Statewide training program.
- » Articulate to the public what is known and not known about autism.
- » Enhance established resources (Autism Outreach Project, Autism Center, Professional Development in Autism approach, Medical Home) to provide information on early detection, treatment, and research findings to the public and to health care professionals.
- » Disseminate evidence-based information through statewide training program.
- » Address the issue of discriminating against high functioning individuals with ASD.
- » Expand intervention from pediatrics to all providers.
- » Use good, evidence-based standards for effective services with necessary resources for weaving intervention services into the lives of individuals of all ages who experience autism.
 - Birth to 3.
 - Ages 4-5.
 - K-Middle School.
 - Middle School to Adult Life.

- Adult Services.
- Family/Community life.
- » Evidence-based standards for effective services should include:
 - An array of strategies, which may include 25 hours per week for early intervention services, one on one instructions, etc.
 - Emphasize cultural competency.
 - Be sensitive to the different ways that people with Autism Spectrum Disorders learn.
 - General education and special education teachers partnering together.
- » Resources and continued development of state, regional, local, district and specialists trained on good autism research based standards for whole life services and supports:
 - Medical/Dental/Mental Health.
 - Family Support/Respite.
 - Personal Care.
 - Education.
 - Post Secondary Education.
 - Assisted Living/Residential.
 - Employment/Supported Employment/Vocational.
 - Trained staff to provide evidence-based services.
- » People who work with children with ASD need to have a minimum level of required training that enables them to be effective. Professionals from many different backgrounds need training:
 - Medical/Dental/Mental Health.
 - Family Support/Respite.
 - Personal Care.
 - Education.
 - Post Secondary Education.

- Assisted Living/Residential.
 - Employment/Supported Employment/Vocational.
 - Emergency preparedness.
 - First responders.
 - Other.
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- » Autism Spectrum Disorder expertise should be present at regional, local and district levels for timely referrals to multiple programs and services without waiting lists through the continuation of our statewide autism leadership (AOP) and development of local training programs (similar to ESD112 Regional Autism Consulting Cadre, University of Washington Autism Center, Seattle and Tacoma, Northwest Autism Center, DOH-CSHCN).
 - » Recommendations from the Autism Task Force should sustain efforts that already exist in the state of Washington and aim to help all kids with disabilities, without overwhelming schools and taking resources away from other groups of students.
 - » Training: Create a statewide training system based on evidence-based practices with regional and local follow-up and consultation; must address multiplicity of audiences that interact with and support people with ASD; and provide training outreach to rural ethnic and culturally diverse populations.
 - » Recommend creating pilot programs where intervention strategies could be piloted, while gathering data and determining if the data could be generalized.
 - » Implement state-wide professional training program, leveraging financial and technical

resources already existing in UW Autism Center, Autism Outreach Project, Autism Cadre, and UW Professional Development in UW Autism Center.

- » Create statewide web-based resources through the University of Washington to provide information on early detection, treatment, and research findings to the public and to health care professionals.
- » Create and disseminate PDFs, informational videos, brochures, and newsletters to provide up-to-date information to parents and professionals.
- » Implement distance learning program to train educators and other professionals.
- » Offer state-wide workshops and in-service training to birth-to-three centers, schools, community agencies, and mental health settings, focusing on the needs of individuals with autism from infancy through adulthood.
- » Provide training to primary care providers in early detection and treatment.
- » Regional Autism Facilitator trainers.
- » Provide ongoing technical assistance and training through regional Autism Centers. Utilize UW technology resources, including: web-based distance learning, telemedicine capability, and K-20 interactive telecommunications network.
- » Enable colleges and universities to develop curriculum for students preparing to practice in professional and educational fields providing services to individuals with autism and their families.
- » Adopt an incentive program to retain and attract a broad spectrum of students preparing to

serve individuals with autism in educational and professional disciplines. The incentive program may include, but not be limited to, loan forgiveness, tax credits, tax deductions and such other appropriate measures as determined by the Ohio General Assembly.

- » Establish standards for teachers working with individuals with Autism, with possible credentialing.
- » Assess regional educational and provider needs.
- » Establish regional Autism Centers to provide training to increase local capacity and technical assistance. Each Center should provide regional training, direct service and technical assistance. Consideration should be given to:
 - Population base.
 - Geographic location.
 - Existing resources (people, space).
 - Proximity to state universities (e.g., WSU, UW).
- » Fund lifespan intervention services (e.g. basic and special education, early intervention services, adult services, vocational services, housing, mental health, residential).
- » Mandate coverage by private insurance and Medicaid (e.g. Katy Beckett—not based on income) for intervention and treatment.
- » Fund the regional centers and related training initiatives.
- » Increase funding for individual and family supports.
- » Improve provider capacity through ideas such as:
 - Pay incentives for special education teachers specializing in autism (i.e. as evidenced by

Funding

- appropriate certification or specialized training in best practice approaches).
 - Competitive pay for ancillary services specializing in autism (as evidenced by experience and training in best practice approaches) and working within the public education system.
 - Coverage by private insurance and Medicaid for IBI (intensive early behavior intervention) and other proven models of treatment, minimum of 25 hours/week (to include coverage of professional to design and supervise programming, and tutors to implement—for in-home or on-site services depending on age and individualized appropriateness for each child).
 - CPT coding including ICD-9, relevant to treatment and services specific to autism.
 - CPT coding/insurance coverage for case management services through Medical Home model.
 - Tuition relief/Student Loan reimbursement assistance for providers (special ed teachers, ancillary service providers, and physicians) specializing in autism, committing to work in rural areas and those areas of ethnic and cultural diversity (i.e., Reservations, Military, etc).
- » Empower educational system through:
- Increased funding for special education earmarked for ASD and in proportion to enrolled students with ASD.
 - Increased funding for early intervention “Children Birth–Three/ITEIP?”
 - Increased funding for basic education.
 - Increased funding for OSPI for use in autism training, programming, resource development, and evaluation. Money should be specifically for providing, or contracting for provision

of: teacher training, ongoing supervision and consultation by “autism professional,” evaluation of school district progress in educating children on the spectrum, development of criteria and standards for assessing progress of students and staff, and development of standardized process and materials for identifying children and coordinating their referral and access to school services.

- » Ensure regional access to services and resources (through the lifespan) through:
 - State funding for development of regional centers throughout the state where none exist, and funding continued development and expansion of services (towards becoming a regional center) in areas where a coordinated effort to provide services has already been established (i.e., UW’s Autism Center and EEU, Tacoma Satellite, Northwest Autism Center, Autism Cadre ESD 112, Yakima Children’s Village, Autism Outreach Project, etc.). Note: Required basic components of centers need to be identified (refer to centers developed in other states – i.e., Florida’s Care System, as well as local input). Individualized short and long-term plans for development (of each identified site) addressing those components are required to assure consistency of comprehensive services across state.
 - Autism Waiver for individual and family supports.
 - State funding to support revision of DDD eligibility requirements providing access to services and resources by individuals on the spectrum and access to respite care (requires appropriate modification of current care assessment tool used for determining personal care hours through Medicaid).

- Medicaid eligibility for coverage per ASD diagnosis unrestricted by family income (i.e., Katy Beckett).
- Provide employers with incentives to hire people with ASD.
- » Provide comprehensive health care and treatment through:
 - Dental care coverage for general anesthesia in providing routine dental care (as appropriate/needed by individual with ASD). For consultation/training from “autism professionals” in ongoing treatment and care using positive behavioral supports (to improve quality and consistency of dental care).
 - Mental health coverage for services for children on the spectrum and for adults on the spectrum. Will require revision of current mental health eligibility requirements and a concurrent revision of training expected of mental health providers (to have autism specialty component).
 - Coverage of mental health services provided within the public school system. Should be a regular presence in every district.
 - Insurance coverage to support CPT coding for biological treatments and pharmacologic treatments, and follow-up.

Assessing Effectiveness of Programs and Services

- » Based on its work over the past few months, the task force recommends a number of additional strategies/programs/interventions.
- » At the same time that the task force makes these recommendations, it is also imperative that a quality assurance process be attached to any new strategies implemented as well as to current efforts in the field. This recommendation is made for two

reasons. First, the task force would like to ensure quality of implementation for any program and would like to begin building evidence-based practice in providing services to people with autism.

- » The task force recommends a quality assurance process be built into any program or service and that the quality assurance process show capacity to assess the effectiveness of the program/service.
- » The quality assurance process should have the following characteristics:
 - Family Friendly including being able to demonstrate that the program/service:
 - ◇ Listens to parents/family. Has a complaint policy that includes, how to make a complaint, who will follow up on complaint, time frames for response to complaint, definition of when complaint is determined to have been addressed, and an appeal process.
 - ◇ Solicits periodic feedback from other people involved with the person.
 - ◇ Encourages family participation, support and involvement.
 - Describe purpose of the program including proposed goals and objectives and how the program will assess achievement:
 - Describe measures/data points designed to determine program/service success.
 - Describe how measures/data points will be taken/collected.

Some examples include reduction in symptoms or medication, increased participation in typical activities, improvements in communication, obtaining and keeping a job, satisfaction with services, observable changes in behavior or

responses, improvement in general or specific health conditions including oral health, improvements in sleep time.

- Demonstrates that the people it hires have the skills, expertise and experience to implement/achieve the program/service purpose/mission.
- Demonstrates it has a training curriculum that ensures the people responsible for achieving its purpose, goals and objectives are current with competent, qualified or licensed practice.

Some examples include teachers, social workers, case managers, and direct support staff are knowledgeable about autism; Individual Family Service or Education or Support (IFSP, IEP, ISP) demonstrate knowledge of autism; IFSPs/IEPs/ISPs document appropriate goals and objectives that are consistent with the individual's needs and measured against individual goals.

- Regularly monitors its achievement of its program purpose, goals and objects and uses its self-monitoring to change, modify and/or improve practice.
- Data collection (prevalence, incidence, service provision, cost analysis) imperative.
- Assessment (for instance Center for Transition and Change) needed.
- Evaluation needed.
- Quality management of services essential.

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ppendix 2

Related Sources of Information Suggested by Stakeholders

Burbacher, T., *Vaccines and Mercury Exposure*, SPOTLIGHT, University of Washington, School of Public Health, 2005

Cure Autism Now (CAN), *Autism Screening and Diagnostic Evaluation: CAN Consensus Statement By the CAN Consensus Group*, CNS Spectrums Journal, 1998

Cutler, Eustacia. Thorn in My Pocket: Temple Grandin's Mother Tells the Family Story. Future Horizons (December 15, 2004)

DEFEAT AUTISM NOW! (DAN!), *Clinical Assessment Options for Children with Autism and Related Disorders: A Biomedical Approach*, Autism Research Institute, January 1995, Revised 1997

Gerlach, Elizabeth K. Autism Treatment Guide. Future Horizons; 3 edition, May 2003

Grandin, Temple. Thinking In Pictures: and Other Reports from My Life with Autism. Vintage, October 29, 1996

Janzen, Janice E. Understanding the Nature of Autism: A Practical Guide. Psychological Corp; Manual edition (November 1998)

Leaf, R., McEachin, J., & Harsh, J.D., A Work in Progress: Behavior Management Strategies & A Curriculum for Intensive Behavioral Treatment of Autism, D R L Book, LLC, May 1999

Maurice, C., Let Me Hear Your Voice, Ballantine Books; Reprint edition, July 19, 1994

McKenna, P., *State Funding for Intensive Early Intervention for Children with Autism: A Review of Successful Strategies*, University of Washington Autism Center, July 2003

National Education Association, The Puzzle of Autism, 2006

Rau, J., *Is it Autism?* Contemporary Pediatrics 2003; 4:54

Seltzer, et al. *Continuity or discontinuity of family involvement with adults with mental retardation following residential transitions.* University of Wisconsin, Center of Human Development and Disabilities – Evaluation, Lyle Romer, Ph.D., DDD; Mental Retardation, 39, 181-194.

Sheehan, S., *The Autism Fight*, The New Yorker, December, 1. 2003

The Brookings Institute and The Help Group Conference Center, Autism and Hope, 2006

UC Davis Health System, UC Davis M.I.N.D. Institute Launches Largest Biomedical Assessment of Children with Autism, March 8, 2006

Appendix 3

Useful Websites Recommended by ATF Members

Autism Society of America

<http://www.autism-society.org>

Autism Speaks

<http://www.autismspeaks.org>

Connections Center – relationship development intervention treatment program for autism spectrum disorders

<http://www.rdiconnect.com/default.asp>

Cure Autism Now

<http://www.cureautismnow.org>

Department of Social & Health Services, Division of Developmental Disabilities. Title: County Services for Working Age Adults, Chapter 71A RCW and Chapter 388-850-035 WAC

http://www1.dshs.wa.gov/pdf/adsa/ddd/policies/policy4.11_07_04.pdf

Families for Effective Autism Treatment – Washington

<http://www.featwa.org/>

First Signs

<http://www.firstsigns.org/>

National Early Childhood Technical Assistance Center (NECTAC)

<http://www.nectac.org/>

Professional Development in Autism Center – UW
<http://www.pdacenter.org>

UW Autism Center
<http://depts.washington.edu/uwautism/>

Appendix 4

PowerPoint Presentations Given at Autism Task Force Meetings

(these presentations are available only on the Autism Website)

University of Washington Autism Center, Geraldine Dawson, PhD, January 4, 2006,

http://www.doh.wa.gov/cfh/mch/Autism/Jan4_06mtg.htm

Project DATA: Developmentally Appropriate Treatment for Autism, Ilene Schwartz, PhD, January 4, 2006.

http://www.doh.wa.gov/cfh/mch/Autism/Jan4_06mtg.htm

OSPI Autism Task Force, Lou Colwell, EdD, December 8, 2005,

http://www.doh.wa.gov/cfh/mch/Autism/Dec8_05mtg.htm

ESD112 Regional Autism Consulting Cadre, Monica Meyer, December 8, 2005,

http://www.doh.wa.gov/cfh/mch/Autism/Dec8_05mtg.htm

University of Washington Autism Center, Felice Orlich, PhD (back-up for Geraldine Dawson), December 8, 2005,

http://www.doh.wa.gov/cfh/mch/Autism/Dec8_05mtg.htm

Northwest Autism Center and Domino Project, Dawn Sidell, RN, representing Northwest Autism Center, December 8, 2005,

http://www.doh.wa.gov/cfh/mch/Autism/Dec8_05mtg.htm

Autism Outreach Project, Carolyn Taylor, representing Autism Outreach Project, December 8, 2005,

http://www.doh.wa.gov/cfh/mch/Autism/Dec8_05mtg.htm

Caring for Washington Individuals with Autism Task Force

Autism: The Public Health Challenge, Geraldine Dawson, PhD, representing the UW Autism Center, November 14, 2005,

http://www.doh.wa.gov/cfh/mch/Autism/Nov14_05mtg.htm

Prevalence of Autism Spectrum Disorders, Riley Peters, PhD, MCH Assessment Manger,

http://www.doh.wa.gov/cfh/mch/Autism/Nov14_05mtg.htm

Making Decisions About Interventions for Students with ASD, Ilene Schwartz, PhD, University of Washington

http://www.doh.wa.gov/cfh/mch/Autism/Nov14_05mtg.htm

PowerPoint Presentation given to March 13, 2006 Autism Task Force by guest speaker Tom Burbacher, PhD. Presentation entitled, Thimerosal in Vaccines: Some Recent Research.

<http://www.doh.wa.gov/cfh/mch/Autism/documents/BurbacherPresentation.pdf>

Appendix 5

Medical Home Checklist

Your child's pediatrician or family physician may not have all of the following pieces of Medical Home in their practice, but it will help to know what to ask for and what you can work on together. You can use this list when choosing a new physician

Your child's primary care doctor and their office is accessible

- Available after hours, on weekends and holidays.
- Accepts your child's health insurance.
- Office and equipment physically accessible to your child.

Staff within your child's primary care office know you and help you

- Know you and your child when you call.
- Recognize and accommodate your child's special needs.
- Respond to requests for prior approvals, letters of medical necessity for your child's insurance, or documentation for other programs and services.
- Provide written materials in a language you understand.

Your child's primary care doctor and office staff help you to coordinate your child's care.

- Follow up with difficult referrals.
- Help you to find needed services such as transportation, durable medical equipment, home care, and ways to pay for them.
- Explain your child's needs to other health professionals.
- Reach out to your child's school or day care providers to help them understand your child's medical condition.
- Encourage and support frequent communication between all persons involved in your child's care (with your consent).
- Organize and attend team meetings about your child's plan of care that include you and other providers.

Your child's primary care doctor respects you and listens to your observations about your child.

- Asks you to share your knowledge about your child.
- Seeks your opinion when decisions are needed.
- Talks to you about how your child's condition affects your family (other children in the family, child care, expenses, work, sleep).
- Acknowledges and respects your family's cultural values and religious beliefs.
- Provides interpreter services, if needed.

Your child's primary care doctor and office staff work with you to plan your child's care.

- Help you set short-term (3-6 months) and long-term (the next year) goals for your child.
- Give you important information, such as recommendations or new treatments, in writing.
- Work with you to create and update a written plan of care for your child's medical and non-medical needs.
- Review your child's medical records with you when needed.
- Help you consider new and emerging treatment choices for your child's condition.

Your child's primary care doctor and office staff support you as a caregiver.

- Help you connect with family support organizations and other parents in your community.
- Provide information on community resources.
- Find and share new information, research or materials that are helpful in caring for your child.
- Help you to advocate on behalf of your child.
- Plan for adult health care services (if appropriate for your child's age).

Adapted from A NEW WAY...A BETTER WAY. The Medical Home Partnership: Building a Home Base for Your Child with Special Health Care Needs: New England SERVE

http://www.neserve.org/neserve/med_hm.html

Texas Medical Home Toolkit

A

ppendix 6

Acronyms

ASD	Autism Spectrum Disorder
CDC	Centers for Disease Control and Prevention
CSHCN	Children with Special Health Care Needs
DDD	Division of Developmental Disabilities
DVR	Division of Vocational Rehabilitation
DOH	Department of Health
DSHS	Department of Social and Health Services
IFSP	Individual Family Services Plan
IEP	Individual Education Plan
ITEIP	Infant Toddler Early Intervention Program
MCH	Maternal and Child Health
MCHAT	Modified Checklist for Autism in Toddlers
NIMH	National Institute of Mental Health
OSPI	Office of Superintendent of Public Instruction
WAC	Washington Administrative Code

Glossary

Appropriate services	Services that are timely, individualized, culturally effective, multidisciplinary, evidence-based, and legally required.
Autism Spectrum Disorder	A disorder that is characterized by impairments in three domains: social interactions, language and communication, and repetitive behaviors. There is wide variability in symptoms and severity, and it may be accompanied by sensory integration difficulties, speech delay, medical conditions, mental retardation, and motor involvement.

Incidence of ASD	Number of new cases of ASD diagnosed in a specific time period
Medical Home	An approach to primary health care that is accessible, continuous, comprehensive, family centered, coordinated compassionate, and culturally effective.
Prevalence of ASD	Number of current cases of ASD

Appendix 7

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