

Caring for Washington Individuals With Autism

December 2006

Recommendations

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Recommendations

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

Infrastructure (IN)

IN-1

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

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.