Autism Guidebook for Washington State

A Resource for Individuals, Families, and Professionals

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For persons with disabilities, this document is available on request in other formats.
To submit a request, please call 1-800-525-0127 (TDD/TTY 1-800-833-6388).

The Autism Task Force (ATF) is grateful to both the Ohio Task Force and the Ohio Parent's Group for their hard work, the creation of these documents, and permission to use their products as a basis for this Washington State Autism Guidebook. Additionally, the ATF extends our thanks to Washington State's Governor Christine Gregoire and the Washington Legislature for recognizing the need and establishing the Caring for Washington Individuals with Autism Task Force. This manual is a direct result of their concern and recommendations.

Introduction

Individuals with Autism Spectrum Disorders (ASD) require individually designed interventions that meet the distinct need of the person. It is important that parents, health care, social services and school professionals, working together as a team, select teaching strategies and methods based on peer reviewed, empirically based, valid evidence. We are at a time in history when we have this knowledge and evidence. To say that a methodology is grounded in scientifically based research means there is reliable, independent evidence and current knowledge that a given program or practice works for an individual with autism. Each individual with autism deserves no less.

This document was developed through the efforts of the Caring for Washington Individuals with Autism Task Force (ATF), a Governor appointed group comprised of parents and professionals, established in 2005 by the Washington State Legislature. The ATF gathered information and consulted with experts and individuals with Autism Spectrum Disorders (ASD) to inform the state and public on:

- Autism services needed
- Autism rates
- Access to care
- Effectiveness of current services
- Other issues or concerns needed to provide sound policy recommendations

Thirty-one specific recommendations emerged from the work calling for improvement of care and outcomes for individuals with ASD.

Broad in nature, these endorsements encompass needed change in systems of infrastructure, treatment, training, and funding in Washington State. Additional individuals provided assistance to develop some of the recommendations by joining subcommittees. The subcommittees focused specifically on plans for Regional Networks, Family-Centered Care, Identification and Tracking, and Education. The combined effort resulted in implementation plans for priority recommendations, one of which was the development of an autism guidebook for individuals with autism—birth through lifespan, for Washington State.

This guidebook is one of the thirty-one recommendations made by the task force in their 2006 report. An additional mandate of the 2007 Legislature directed the ATF and DOH to produce the manual. Funds to print the guidebook were provided by the Autism Awareness: Partnership for Change federal grant.

The Autism Guidebook for Washington State: A Resource for Individuals, Families, and Professionals, is based on the model of the *Service Guidelines for Individuals with Autism Spectrum Disorder/Pervasive Developmental Disorder (ASD/PDD) Birth through Twenty-One* (2004) and some additional content from the 2007 *Ohio's Parent Guide to Autism Spectrum Disorders*. Ohio graciously gave us permission to use their guidebooks as a starting point for this Washington State book.

We would like to acknowledge Ohio's willingness to share their resources with a statement from Kay Treanor of the Ohio Developmental Disabilities Council:

> *The Service Guidelines originated as the result of the dedication of many knowledgeable people in Ohio who met as a task force and volunteered countless hours over several years to bring this information together. Its purpose is to provide information that will help families, educators, medical professionals, and service providers make informed decisions about children and young adults with autism or other pervasive developmental disorders. It provides recommendations as to best practices for both assessment and the provision of treatment and care for this rapidly growing population, without endorsing any one treatment methodology. It is our hope that you too will find this information beneficial*
>
> Kay Treanor, ODDC, 2008

The ATF experts spent considerable time reviewing sections on various topics and then blending new evidence based information and rewriting to produce a guidebook double the size of the original Ohio book. The task force made it state specific, brought the information up to date, filled in gaps in essential information, and added references to all. It is important for families and professionals who struggle to understand the complexities of ASD to know exactly where the information originated. The ATF created a focus that provides familiarity with best practices in assessment, the provision of treatment and care, and some understanding of the arrangement and interrelationships of agency systems, laws, and services that apply.

At the back of the Guidebook is the Autism Lifespan Resource Tree and Directory, a five-page document designed as a quick reference to autism services and supports in Washington State. Another location with internet addresses and phone numbers can be found in Appendix 16: Getting Connected. Please be advised that the names, numbers, and addresses in both of these resources are as complete and accurate as possible at this point in time of publication.

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Autism Lifespan Resource Tree and Directory

Chapter 1: User Guide

Purpose and Source

These guidelines offer basic concepts in providing supports for individuals with Autism Spectrum Disorder (ASD). The information and recommended strategies and modifications were compiled by committees and agreed upon by the Caring for Individuals with Autism in Washington Task Force, referred to as the Autism Task Force or ATF.

Introduction

The ATF recognizes that finding and maneuvering through the various systems in Washington State can sometimes be tedious and frustrating. Throughout the document there are multiple references to various federal laws and state agencies. A summary of pertinent federal laws and the state agencies affected by and involved with the laws can be found in the first few sections of the Appendix.

The guidelines are intended to serve as an informational tool to assist in the navigation of available treatments and services, and to understand the language and issues currently relating to ASD. They can be viewed as a map to the development of independence for the individual with ASD at the highest level possible in all life areas. The guidelines are not a required standard of practice for the education of these individuals in Washington State.

These guidelines are intended to provide recommendations based on current knowledge about how to assess the needs of individuals and obtain or deliver appropriate services and supports to children and adults with autism spectrum disorder. They are intended to help individuals with the disorder move from one developmental level to another and gain momentum in the process. These guidelines have a primary focus on individuals, from infancy throughout the lifespan. The basis for all the guidelines is to acknowledge a continuing process of change and growth.

Several decades ago, if a child was diagnosed with autism, there was little hope for leading anything close to a "normal" life. In fact, many parents were encouraged by professionals at the time to place their children with autism into institutional care to spare the families the stress and heartache of attempting to raise the children. However, recent research has demonstrated that by providing appropriate services and supports at appropriate developmental levels, significant gains in most life areas can be achieved and the person with ASD can thrive.

Also, due to a shift to the "spectrum" view of ASD, we are better able to identify and assist those individuals who have less severe forms of the disorder. These individuals were most often left undiagnosed in the past and did not receive many appropriate services or supports even though we now know they could have benefited from them. Improvements in diagnosis is essential for optimizing potential outcomes in ongoing treatment and intervention for individuals with autism. This shift will require changes in attitudes, policies, and the allocation of resources to address the needs of every person with ASD in a fair and appropriate manner.

How to Use This Document

Description

- Definition
- Medical Aspects
- Components of Learning
- Components of Instruction and Resources
- Community Transitions
- Future Life Planning
- Autism Awareness
- Training in the Community
- Advocacy

We recommend that the user of this document not look at the sections in isolation. Given the complex nature of ASD, delivery of educational supports often requires consideration of many aspects of the person simultaneously. Cross-referencing is provided to assist the reader with making a more comprehensive understanding of each of the topics. Being familiar with all contents of this document is ideal.

There is a wealth of knowledge and information included in the supplemental pieces of the Appendix. Included is information on federal disability laws, the Washington State agency appointed to carry out the law, and the Washington Administrative Code (law) that applies. These incorporate Child Find Information, Washington's System of Services Birth to Three, and Special Education age 3 through 21. The ATF recommends reading carefully through Appendices 1, 2, and 3 to discover how the laws might apply to individual situations and which agency has been appointed responsible for services under state and federal law.

There are other appendices on Educational Components, Medical Aspects, Frequently Used Terminology, References for all the citations, and a Getting Connected section with internet addresses and some phone numbers. All the information is provided to give the reader background and more insight on issues.

This document should be a part of your regular planning and training process. It should be used in tandem with continuous in-service training for families, educators, medical professionals, care providers and other service providers.

Practitioners and families are encouraged to use the information provided in these guidelines recognizing that the services should always be tailored to the individual. Not all of the recommendations will apply in every circumstance.

Recommended Process

- When using this document to address a particular need, identify in the Table of Contents the section that most closely relates to the topic. Read the entire section and any referenced sections.

Work with a team to develop a plan, whether it be education, health care, or social services. When related issues arise in the planning process, review those topics and referenced sections.

- Periodically review the progress, implementation, and plan. The guidelines include recommendations for assessment, and can be used to generate next steps.
- Refine the plan and its implementation on a regular basis, returning to the Guidelines for further information and recommendations.

What this Document is NOT

These guidelines are not a required standard of education for individuals with ASD in Washington. They are not intended to support any specific intervention, treatment program, methodology, or medication.

Chapter 2: Introduction to Autism

There are several different definitions of autism as the definitions serve different purposes. The introduction gives a broad general description and a global "picture" about the subject of autism. It gives a lot of information and the knowledge is easily understood.

Treatment strategies for ASD include both medical treatment and educational interventions. The medical definition is required for a diagnosis of autism and must be made by a psychologist, psychiatrist, or a physician using criteria from the *Diagnostic and Statistical Manual of Mental Disorders, DSM-IV* (see Chapter 4: Medical Aspects). The diagnosis then helps the individual to obtain needed treatments, medications, or therapies.

A medical diagnosis is not required for an education identification of ASD, nor does it automatically guarantee identification. Both definitions identify the difficulties experienced by individuals with ASD in the areas of communication, socialization, and behavior. The educational definition was designed to identify children eligible for special education services under the federal Individuals with Disabilities Education Act (IDEA) first enacted in 1991. Additionally, there is a Washington State law (WAC) describing autism. It is used to determine eligibility for special education services in our state (see Appendix 3: Special Education).

What is Autism or Autism Spectrum Disorder?

Autism is a complex neurodevelopmental disorder occurring in 1 in 150 individuals with more frequent occurrence in boys than girls (Centers for Disease Control and Prevention [CDC] 2007). Classified as one of the five Pervasive Developmental Disorders (Diagnostic and Statistical Manual of Mental Disorders, IV, TR, 2000), autism is a neurological disorder that impacts brain development in social interaction, communication and repetitive behaviors. The onset of symptoms is generally within the first three years of life, although the presentation varies widely among individuals.

The pervasive developmental disorders encompass behavioral impairments across three domains of development:

- Qualitative impairments in social interaction
- Qualitative impairments in communication
- Restricted, repetitive and stereotyped patterns of behavior, interest and activities (Centers for Disease Control and Prevention, 2007)

There are a number of other common findings in individuals with autism that are not part of the diagnostic criteria. These may include unusual responses to sensory stimulation, behavioral disturbances and significant strengths and weaknesses in cognitive characteristics. The definition of autism has broadened so that autism is now seen as a spectrum disorder. In recent years, the conceptualization and criteria defining the condition called "autism" have evolved. For these guidelines, the panel agreed to use

the terminology of "Autism Spectrum Disorder" (ASD) which would include the disorders commonly diagnosed as Autism, Asperger Disorder, and Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS). The majority of specialists believe that the boundaries along the continuum overlap to a large degree.

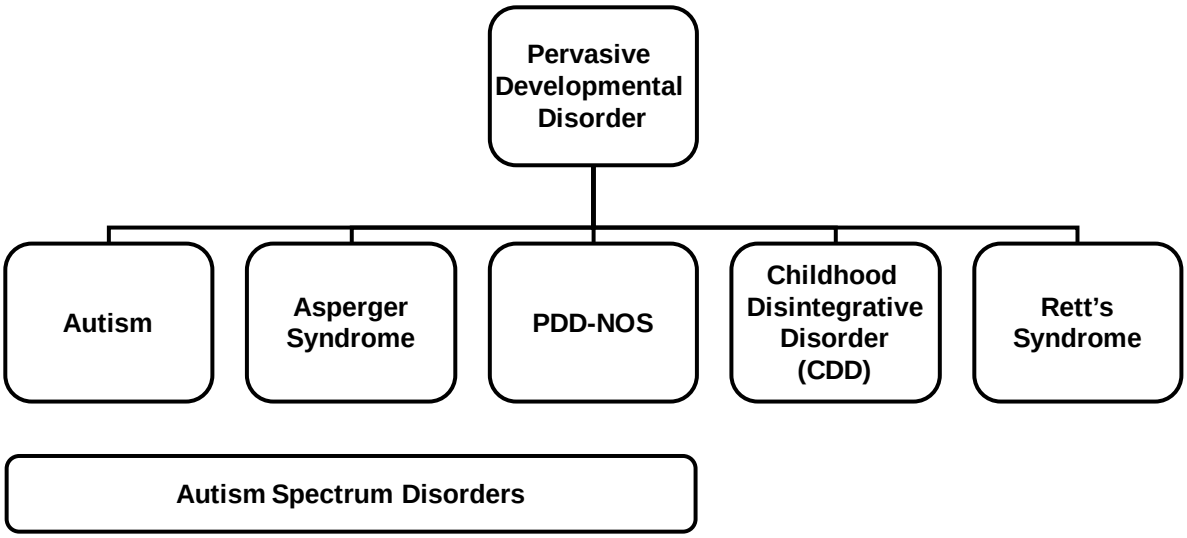
Autism is more common than previously realized, in part due to the broader definition and inclusion of higher functioning autism in recent years. Earlier studies suggested that about three to four individuals in 10,000 were affected by autism (Fombonne, 2003). Researchers observed an increase in the rate of individuals diagnosed with ASD in the past decade. The most recent estimate from the CDC is one out of every 150 children in the communities studied has an ASD (2007).

In addition to inclusion of high functioning autism, the increase in the number of people with autism spectrum disorders may also be a result of improved diagnosis. However, other possibilities are being considered including environmental and genetic factors.

Chapter 3: Defining Autism

Pervasive Developmental Disorders (PDD)

Autism is one of five disorders that falls under the umbrella of Pervasive Developmental Disorders (PDD), a category of neurological disorders characterized by "severe and pervasive impairment in several areas of development" (Autism Society of America, 2008)



Autism is a complex neurobiological disorder that typically lasts throughout a person's lifetime. It is part of a group of disorders known as autism spectrum disorders (ASD). Today, 1 in 150 individuals is diagnosed with autism, making it more common than pediatric cancer, diabetes, and AIDS combined. It occurs in all racial, ethnic, and social groups and is four times more likely to strike boys than girls. Autism impairs a person's ability to communicate and relate to others. It is also associated with rigid routines and repetitive behaviors, such as obsessively arranging objects or following very specific routines. Symptoms can range from very mild to quite severe. All of these disorders are characterized by varying degrees of impairment in communication skills and social abilities, and also by repetitive behaviors (Autism Speaks, 2008).

PDD Categories and Diagnostic Criterias

Pervasive Developmental Disorders are a group of conditions with common impairment in the domains of socialization and communication. These include Autism, Asperger Syndrome, Pervasive Developmental Disorder-Not Otherwise Specified, Childhood Disintegrative Disorder, and Rett's Syndrome. Autism, Asperger Syndrome, and PDD-NOS fall under Autism Spectrum Disorder.

Autism is the classic form of ASD with a prevalence of about 11:10,000 and a male/female ratio of 3-4:1. Diagnosis is optimally made between age sixteen months to three years, with some children showing features in the first year of life. Individuals with this diagnosis have dysfunction in three core domains.

- **Qualitative Impairment in Socialization**
  Socialization abilities are most severely affected in the early preschool years with the child either socially unavailable or a social loner. Social skills improve over time, but still show variable dysfunction ranging from remaining a social loner to acquiring social skills that are stilted and pedantic.

- **Qualitative Impairment in Communication**
  Impairment in communication ranges from absence of an apparent desire to communicate to excessive speech with poor interactive conversation. All individuals have impairment in pragmatic abilities, such as poor eye contact, voice modulation, and use and understanding of gestures and other nonverbal body/facial expressions.

  They are literal in interpretation of others' comments and actions and have difficulties with insight into others' actions and perspectives. Echolalia is the immediate and involuntary repetition of words or phrases spoken by others. It is usually present in a transient or permanent manner. Play usually shows a deficit in imagination and symbolic features, although some children will develop a restricted pretend play.

- **Restricted Interests and Repetitive, Stereotypic Behaviors**
  All individuals with autism have restricted activities and interests that can range from repetitive motor actions such as opening and closing doors to finger flicking, spinning and lining objects to fascinations in mechanical and cognitive themes. Resistance to change in routine is commonly seen in the preschool years and may persist to adulthood.

Other Members of the PDD Category

- **Asperger Syndrome** typically becomes apparent in the pre-school years with challenges in socialization, interpreting social cues and naive/unusual behavior. Language, while within age expectations in achievement of developmental milestones, has associated problems in abstraction, interpretation and pragmatics. Areas of fascination are usually paramount. By definition, individuals with Asperger Syndrome have cognitive and adaptive skills within the average range. Many individuals with Aspergers struggle with executive functioning challenges and co-occurring mental health issues.

- **Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS)** is applied to children who have some, but not all, of the features of autism (either quantitatively or qualitatively). All individuals have impairment in socialization with either impairment in communication or restricted activities/interests. This category is not as well defined as the others and may inadvertently be applied to children with socialization difficulties due to other conditions.

- **Childhood Disintegrative Disorder** has behavioral features similar to autism with onset between ages two to ten years after an apparently normal early childhood. It is sometimes associated with specific medical disorders and has a worse prognosis for significant improvement.

- **Rett's Syndrome** occurs after an apparently normal early infancy with a stagnation and loss of developmental skills between ages five to thirty months. This is associated with a deceleration of head growth, loss of purposeful hand use and replacement with stereotypic hand movements such as hand wringing and mouthing, gradual appearance of gait unsteadiness, and severe impairment in expressive and receptive language and in cognitive abilities. This disorder is primarily limited to girls, who may transiently show impairment with socialization during its evolution. Most develop seizures. Rett's Syndrome is caused by an abnormality in the MECP2 gene on the X chromosome.

Autism spectrum disorders and developmental disabilities are complex by nature and cross all learning and lifespan of an individual, in school and at home. While there is no known cure for autism, it is treatable and this includes both medical and educational interventions.

Autism is one of the disabilities specifically defined in the federal Individuals with Disabilities Education Act (IDEA, 2004) and the Washington Administrative Code (WAC) 392-172A-01035 (2007).

Individuals With Disabilities Education Act (IDEA)

Federal Regulation-34 CFR 300.7 (c)(1) (2004)

I. Autism is a developmental disability significantly affecting verbal and non-verbal communication and social interactions, generally evident before age three, that adversely affects a child's educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in routine, and unusual responses to sensory experiences. The term does not apply if a child's educational performance is adversely affected primarily because the child has a serious emotional disturbance, as defined in paragraph (b) (9) of Federal Regulation 34 CFR 300.7

II. A child who manifests the characteristics of "autism" after age three could be diagnosed as having "autism" if the criteria in paragraph (I) of this section are satisfied.

Washington State

WAC 392-172A-01035 - Child with a Disability or Student Eligible for Special Education

(1) (a) Child with a disability or as used in this chapter, a student eligible for special education means a student who has been evaluated and determined to need special education because of having a disability in one of the following eligibility categories: Mental retardation, a hearing impairment (including deafness), a speech or language impairment, a visual impairment (including blindness), an emotional behavioral disability, an orthopedic impairment, autism, traumatic brain injury, an other health impairment, a specific learning disability, deaf-blindness, multiple disabilities, or for students, three through eight, a developmental delay and who, because of the disability and adverse educational impact, has unique needs that cannot be addressed exclusively through education in general education classes with or without individual accommodations, and needs special education and related services.

(b) If it is determined, through an appropriate evaluation, that a student has one of the disabilities identified in subsection (1)(a) of this section, but only needs a related service and not special education, the student is not a student eligible for special education under this chapter. School districts and other public agencies must be aware that they have obligations under other federal and state civil rights laws and rules, including 29 U.S.C. 764, RCW 49.60.030, and 43 U.S.C. 12101 that apply to students who have a disability regardless of the student's eligibility for special education and related services.

(c) Speech and language pathology, audiology, physical therapy, and occupational therapy services, may be provided as specially designed instruction, if the student requires those therapies as specially designed instruction, and meets the eligibility requirements which include a disability, adverse educational impact and need for specially designed instruction. They are provided as a related service under WAC 392-172A-01155 when the service is required to allow the student to benefit from specially designed instruction.

(2) The terms used in subsection (1)(a) of this section are defined as follows:

(a) (i) Autism means a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three, that adversely affects a student's educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences.

(ii) Autism does not apply if a student's educational performance is adversely affected primarily because the student has an emotional behavioral disability, as defined in subsection (2)(e) of this section.

(iii) A student who manifests the characteristics of autism after age three could be identified as having autism if the criteria in (a)(i) of this subsection are satisfied. (Statutory Authority: RCW 28A.155.090(7) and 42 U.S.C. 1400 et. seq. 07-14-078, § 392-172A-01035, filed 6/29/07, effective 7/30/07, accessed May 20, 2008.

Diagnostic and Statistical Manual of Mental Disorders IV TR

Diagnostic Criteria for 299.00 Autistic Disorder

(I) A total of six (or more) items from A, B, and C, with at least two from A, and one each from B and C:

(A) Qualitative impairment in social interaction, as manifested by at least two of the following:

1. Marked impairments in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body posture, and gestures to regulate social interaction.
2. Failure to develop peer relationships appropriate to developmental level.
3. A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people, (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people).
4. Lack of social or emotional reciprocity (note: in the description, it gives the following as examples: not actively participating in simple social play or games, preferring solitary activities, or involving others in activities only as tools or "mechanical" aids).

(B) Qualitative impairments in communication as manifested by at least one of the following:

1. Delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime).
2. In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others.
3. Stereotyped and repetitive use of language or idiosyncratic language.
4. Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level.

(C) Restricted repetitive and stereotyped patterns of behavior, interests and activities, as manifested by at least two of the following:

1. Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus.
2. Apparently inflexible adherence to specific, nonfunctional routines or rituals.
3. Stereotyped and repetitive motor mannerisms (e.g hand or finger flapping or twisting, or complex whole-body movements).
4. Persistent preoccupation with parts of objects.

(II) Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years:

(A) Social interaction

(B) Language as used in social communication

(C) Symbolic or imaginative play

(III) The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

Chapter 4: Medical Aspects

This section describes issues related to diagnosis and medical concerns for individuals with Autism Spectrum Disorder (ASD). It includes guidelines for medical assessment and intervention in a wide range of medically related areas. Many of the areas involve daily living skills such as feeding, sleeping, and dental care. Others are psychosocial in nature, and include anxiety, tics, and mood disorder. This section is best used in conjunction with the rest of the document because medical interventions alone are not sufficient to improve behavior or maximize learning (National Institute of Mental Health, 2007). It is, however, important to address potential medical problems because they can significantly impact development of social, cognitive and academic skills (American Academy of Pediatrics, 2007).

Screening and Diagnosis

There is no blood test to determine if a child has an autism spectrum disorder. The diagnosis is referred to as a descriptive diagnosis, meaning the diagnosis is based on observation of the child's behavior. The American Academy of Pediatrics (AAP, 2007), the American Academy of Neurology (2003), and the Child Neurology Society recommend developmental screening for young children at all well-child check-ups with an autism specific screen at 18 months of age. Due to potential regression, an additional autism screen is recommended at 24-30 months of age.

Medical Key Points:

- **Early identification as part of well-child care visits.**
- **Implementation of testing for identifiable etiologies.**
- **Monitoring for co-existing conditions.**
- **Knowledge of pharmacologic and complementary medicine options.**

Screening tools may include the Modified Checklist for Autism in Toddlers (M-CHAT) and are available at **www.aap.org** (see Appendix 11: American Academy of Pediatrics - Clinical Guidelines on Autism). People with ASD can have two or more separate diagnoses, including mental health, medical conditions or other developmental disabilities. This is referred to as dual diagnosis, comorbidity, or co-existing conditions.

Ideally, care for the individual would take place in one setting. Within the school-age population, children who are exhibiting a concerning combination of language, social and behavioral difficulties should be referred for a more detailed evaluation. At risk children include those with social-practical language difficulties, restricted and or intense interests, and significant challenges in social initiation and or both.

The evaluation of all children for a possible ASD diagnosis should include consultation with a medical professional experienced with the autism spectrum. These professionals include child neurologists, child and adolescent psychiatrists, and developmental and behavioral pediatricians, as well as general pediatric specialists with expertise in ASD. A complete history and physical examination should be performed, with emphasis on neurodevelopmental and general medical history, family history of individuals with similar difficulties or known medical history of neurological or developmental conditions, relevant documentation

from previous evaluations, and physical or behavioral findings suggestive of specific genetic, metabolic, neurological or other medical conditions.

Since some medical disorders are associated with or appear similar to ASD, the medical evaluation is needed before any definitive diagnostic statement regarding ASD is made. Medical tests can be helpful in defining an underlying etiology (study of causes) for ASD, or indicating the most helpful treatment. An identifiable cause is present in only a small percentage of this population. According to the American Academy of Neurology and the Child Neurology Society (2006), there are other appropriate screening tests the doctor may order when autism is suspected (see Appendix 12 for complete clinician guidelines).

These include:

1. Genetic tests, specifically high resolution chromosome analysis studies (karyotype) and DNA analysis for Fragile X, because some causes of autism may be inherited—or genetic. Genetic testing can provide information about any specific inherited problems, genetic defects, or nervous system abnormalities the child may have.

   Fragile X is caused by an inherited change in a specific gene. A few children with autism test positive for Fragile X. The doctor should order the test if there is a family history of developmental problems, neurological conditions or if the child has certain physical signs.

2. A relatively new technology called array comparative genome hybridization, or CGH, has dramatically increased the number of certain types of identified chromosomal abnormalities (especially micro-deletions and micro-duplications) not identified using the high-resolution karyotype. While not yet standard, it is reasonable to consider a CGH in children with ASD, particularly if karyotype and Fragile X testing are unremarkable/not conclusive.

3. Electroencephalography (EEG) is indicated only in some individuals, such as those with a history of autistic regression (normal developmental progress with loss of functional language and or social skills) and in those with the clinical suspicion for seizures, among other indications. The EEG study should be done in the awake and sleep state, recording at least one complete sleep cycle. Because some medications used for sedation for sleep can transiently suppress epileptiform activity, sleep should be recorded with natural onset (such as naptime or overnight sleep) or with medication that does not affect epilepsy activity. There are some data to suggest that some aspects of ASD improve if a co-occurring seizure disorder is diagnosed and adequately treated.

4. Other selective metabolic tests may be ordered to see if there is a genetic or non-genetic condition that affects the child. A doctor might order metabolic tests if there are other specific symptoms such as lethargy or cyclic vomiting.

5. Laboratory investigations include formal hearing (audiological) evaluation for children with developmental delay or autism.

6. Screening for vision issues.

7. Skin Wood's lamp assessment should be performed to assess for a skin-brain (neurocutaneous) disorder, such as tuberous sclerosis.

8. Lead screening may be ordered if there is a risk that the child might have lead poisoning or in the case of developmental delay. Since some children with autism tend to eat non-food items and lead may be found in paint chips, the doctor may order a blood test for lead screening.

9. Evaluation of Gastrointestinal (GI) Dysfunction. Despite second-hand reports, no causal relationship has been established between gastrointestinal dysfunction and ASD. Since individuals with ASD can have GI dysfunction of diverse etiology, such as gastroesophageal reflux, chronic constipation, and disaccharidase deficiency, the evaluation should be based on the clinical presentation and not necessarily on the diagnosis of ASD.

10. Brain imaging, such as MRI, rarely shows any significant abnormality in individuals with ASD unless there is a co-existing condition for which imaging is indicated, such as non-familial microcephaly or macrocephaly, regression, seizures or focal neurologic features.

11. Other tests should be ordered as clinically indicated and not because of the diagnosis of ASD. Children with developmental or cognitive impairment and ASD may be candidates for testing for inborn errors of metabolism, including amino and organic acid assays. Other studies such as allergy testing, immune system workup and heavy metal assays should be done only if there are clinical features of these types
of disorders.

12. Psychological tests and speech and language tests are likely to be ordered to help plan for a child's education (Neurology 2000 and National Guidelines Clearinghouse, 2006).

For more information, a parent fact sheet on screening and diagnosing of children with autism and follow up test information is available online from the American Academy of Neurology and Child Neurology Society (2008) at **http://aan.com/professionals/practice/guidelines/guideline_summaries/Autism_Guideline_for_Patients.pdf**.

For general practice providers and pediatricians, see the AAP guidelines in Appendix 11 or online at professional resources **www.aap.org/healthtopics/Autism.cfm**. Additional AAP materials are detailed on page 15 under the AAP toolkit.

School-age Diagnosis

Similar to the preschool age child, the diagnostic assessment of a school-age child should occur through a multidisciplinary approach including assessment of cognitive, language, motor and social skills. In addition to a medical evaluation, school-age children should undergo formal psychological assessment by a child psychologist experienced in evaluating children with ASD. As a component for this assessment, the use of well-recognized diagnostic tools is imperative because of the presence of less obvious symptoms in this age group.

The diagnostic assessment of a school-age child should occur through a multi-disciplinary approach.

Evaluation by a speech and language pathologist with expertise in assessing children with ASD is useful, even in a child with apparently normal speech, in part to examine social and practical skills.

The school has a role in the diagnostic assessment of a school-age child for possible ASD. In addition to being a source of referral for diagnostic evaluation, school personnel can assist by providing accounts of behavioral observations and academic and psychological testing information. For some children, a school visit by a member of the diagnostic team may be valuable. The diagnostic assessment of a school age child should occur through a multidisciplinary approach.

The family is an essential member of the diagnostic team. Family members contribute by providing important historical information. They can optimize their roles by becoming familiar with the features of ASD and helping the diagnostic team recognize the features that may or may not be present in the child.

Diagnostic and Screening Instruments

The following instruments are used to diagnose or assess the clinical course of children with ASD. They measure function and dysfunction across the various areas of ASD. Please note that those using these instruments for screening and diagnostics should have a good knowledge of ASD and training in the use of the different instruments. This is by no means meant to be a complete listing of tools as research continually evolves to develop more effective diagnostic instruments.

Diagnostic Tools

Asperger Syndrome Diagnostic Scale (ASDS)

The ASDS is a quick, easy-to-use rating scale that can help determine whether a child is at-risk for Asperger Disorder. Anyone who knows the child or youth well can complete this scale. Parents, teachers, siblings, paraeducators, speech and language pathologists, psychologists, psychiatrists, and other professionals can answer the 50 yes or no items in 10 to 15 minutes. Designed to identify Asperger Disorder in children ages five through eighteen years, this instrument provides an AS Quotient that tells the likelihood that an individual has Asperger Disorder (Myles, Beck, Simpson, 2001).

Other screening instruments for Aspergers may include the Social Communication Questionnaire, Social Responsiveness Scale, Asperger Syndrome School Questionnaire and the Children's Communication Checklist.

Autism Diagnostic Interview—Revised (ADI-R)

The ADI-R is a standardized semi-structured investigator-based interview of individuals with ASD. It can be used for children with mental age at or above eighteen months. There is good supporting research to confirm its reliability and validity. The short form of the ADI-R takes approximately one hour to complete. The long form is more lengthy and is primarily used in research studies (Lord, Rutter, Le Couteur, 1994).

Autism Diagnostic Observation Scale (ADOS)

The ADOS is a structured observation schedule for the diagnosis of ASD. It focuses on qualitative features of socialization and communication and has an interactive component. Several versions are available, including one for children who are not yet using phrased speech. Since it is used in a highly structured environment, it may not reflect the more subtle features of ASD. Therefore, observations in non-structured settings and parent interview may be necessary (Lord et. al., 2000).

Gilliam Autism Rating Scale (GARS)

The GARS is based on the DSM-IV definitions of ASD and has four sub-tests: stereotyped behaviors, communication, social interactions, and developmental disturbances. This rating scale has good reliability and validity when used for the identification and diagnosis of individuals at or above age three. This scale can be easily and quickly completed by individuals who best know the child (Gilliam, 1995).

Screening Tools

Autism Behavior Checklist (ABC)

The ABC is a 57-item checklist that can be used as a screening instrument. It is used to estimate the severity of autistic features in an individual and to follow these features over time. It is not as reliable as the ADI-R (Krug, Arick, Almond, 1980).

Autism Screening Instrument of Educational Planning (ASIEP-2)

The ASIEP-2 rates individuals at or above eighteen months of age in five areas (sensory, relating, body concept, language, and social self-help.) It is used for evaluations and monitoring of individuals with ASD features (Krug, Arick, Almond, 1993).

Checklist for Autism in Toddlers (CHAT)

The CHAT is a brief checklist to screen for ASD/PDD in children aged 16-30 months. It has two components (Baron-Cohen, Wheelwright, Cox, et al., 2000):

1. A short list of questions for the primary caregiver .
2. Observations in an office setting of behavioral features of ASD.

Two studies have validated its usefulness as a screening tool for children with full features of ASD and, to a lesser degree, for children with high-functioning autism or Asperger Disorder. Those are *The Checklist for Autism in Toddlers*, adapted from Baron-Cohen and Gillberg's *Can Autism Be Detected at Eighteen Months? The Needle, the Haystack, and the CHAT* (1992).

Modified Checklist for Autism in Toddlers (M-CHAT)

The M-CHAT is an expanded American version of the original CHAT from the U.K. The M-CHAT has 23 questions using the original nine from the CHAT as its basis. Its goal is to improve the sensitivity of the CHAT and position it better for an American audience (Robins, Fein, Barton, Green, 2001).

Pervasive Developmental Disorder Screening Test (PDDST)

The PDDST is a screening tool that can be used in multiple settings. Stage 1 is to be used in a primary care setting, Stage 2 for developmental disorders, and Stage 3 in a specialty clinic for children with ASD. It consists of a checklist of core areas of dysfunction and ASD based on parental report. The PDDST is designed as a screening test and is a parent-report measure. As such, it does not constitute a full clinical description of early signs of autism but does reflect those early signs that have been reported by parents and correlated with later clinical diagnosis (Siegel, 2001).

Psychoeducational Profile—Revised (PEP-R)

The PEP-R offers a developmental approach to the assessment of children with autism or related developmental disorders. It is an inventory of behaviors and skills designed to identify uneven and idiosyncratic learning patterns. The test is most appropriately used with children functioning at or below the preschool range and within the chronological age range of six months to seven years.

The PEP-R provides information on developmental functioning in imitation, perception, fine motor, gross motor, eye-hand integration, cognitive performance, and cognitive verbal areas. The PEP-R also identifies degrees of behavioral abnormality in relating and affect (cooperation and human interest), play and interest in materials, sensory responses, and language (Schopler, Reichler, Bashford, Lansing, Marcus, 1990).

Adolescent and Adult Psychoeducational Profile (AAPEP)

The AAPEP extends the PEP-R (see description above) to meet the needs of adolescents and adults. (Mesibov, Schopler, 1988).

Functional Assessments

Real Life Rating Scale

The Real Life Rating Scale (RLRS) assesses function of 47 behaviors. It can be used to monitor the effects of treatment in multiple environments and can be repeatedly used without affecting intra-observer reliability (Ritvo, Freeman, Yokota, Ritvo. 1986).

Promotional Training Programs

Several initiatives concerned with autism awareness for health care providers, parents, and early learning educators are now available. These education programs will increase the concept of early identification by health care providers and early learning specialists. Additionally, the materials teach parents how to recognize developmental issues and advocate on behalf of their children in the process of searching for a diagnosis.

First Signs Program

The First Signs educational and training program incorporates an integrated mix of mailings, public service announcements, press activities, training, research, and web site materials at www.firstsigns.org. These provide essential developmental information, an explanation of the screening process, a systematic guide to each stage of the process, listings of available local and national resources, and links to research, books, articles and programs nationwide.

The program features the First Signs Screening Kit, which includes an educational video ("On the Spectrum: Children and Autism"), screening guidelines based on the practice parameter and endorsed by the AAP, highly validated developmental and autism screening tools, a pediatric practitioner's referral guide to early intervention, and a developmental milestones wall chart.

Currently, First Signs uses the M-CHAT in screening for autism. The following general developmental screening tools are among those used in the First Signs program, although new tools, both for general development and autism, continue to be evaluated.

- **Parents Evaluation of Developmental Status (PEDS)** is a parent questionnaire which is 70 to 80 percent accurate in identifying children with disabilities from birth through eight years. It can be administered by a wide range of health care professionals or office staff (Glascoe, Robertshaw, 2000).
- **Ages and Stages Questionnaire (ASQ)**, developed by Diane Bricker, Ph.D., and Jane Squires, Ph.D., identifies children ranging in age four months through five years experiencing developmental delays. It is a series of questionnaires that works well when used to stimulate conversations with parents or caregivers about a child's development and any concerns they may have (1999).
- **Communication and Symbolic Behavior Scales Developmental Profile Infant-Toddler Checklist (CSBS DP)**, developed by Amy M. Wetherby, Ph.D., CCC-SLP, and Barry M. Prizant, Ph.D., CCC-SLP has 24 multiple choice questions to be completed by a parent or caregiver. It is used to identify developmental delays in children ranging from age six through twenty four months (2001).

Learn the Signs. Act Early.

The Centers for Disease Control and Prevention (CDC) under the federal agency of the Department of Health and Human Services collaborated with many partners to develop a promotional campaign to increase national autism awareness and benefit children. The campaign, called "Learn the Signs. Act Early: It's time to change how we view a child's growth" targets health care providers, parents, and early educators. The partners coming together in this effort include the American Academy of Pediatrics, the Autism Society of America, Autism Speaks, First Signs, the Organization for Autism Research, the CDC, and many community champions.

The following are objectives of the campaign:

- Increase awareness of developmental milestones and early warning signs.
- Increase knowledge in the benefits of early action and early intervention.
- Increase parent-provider dialogue on the topic of developmental milestones and disorders.
- Increase early action on childhood developmental disorders.

The promotional materials consist of distinct resource kits for health care professionals, parents, and early educators. The supplies include posters, fact sheets, informational cards, CD-ROMs, flyers, and growth charts. The resources are free and downloadable from the web site or can be obtained through the mail or by phone. More information can be found at the CDC web site: **www.cdc.gov/ncbddd/autism/actearly/**.

American Academy of Pediatrics (AAP) Toolkit

This toolkit was developed to support health care professionals in the identification and ongoing management of children with ASD in the medical home. The AAP released its pediatric toolkit with an extensive array of resources for caring for children with autism. The information can be accessed on the web or through a CD-ROM, "Autism - Caring for Children with Autism Spectrum Disorders: A Resource Toolkit for Clinicians."

A multifaceted clinical resource, the toolkit has the following practice tools and resources: (1) identification, (2) referrals, (3) physician fact sheets, and (4) family handouts. To view a detailed product profile with sample tools and resources, go to: **www.aap.org/publiced/autismtoolkit.cfm**.

Medical Intervention for Individuals with ASD

Autistic Spectrum Disorders (ASDs) are now recognized as neurobiologically based conditions. ASDs, similar to other neurodevelopmental disabilities, are generally not "curable," and individuals with ASD require ongoing medical monitoring and care, as would any person with a chronic medical condition. This care should occur under the supervision of a medical professional, such as a child psychiatrist, general or developmental pediatrician, or pediatric neurologist. For an adult individual, the medical professional could be a psychiatrist, a primary provider, or a neurologist. In all instances it should be a medical professional with expertise in working with individuals with ASD.

The role of the medical practitioner starts with appropriate identification and continues with medical testing and monitoring for co-occuring conditions and their treatments.

The AAP calls for comprehensive care and care coordination to take place in a medical home setting. This model of care recognizes the need for primary care doctors to treat the whole patient by coordinating care among specialists, and involving and supporting the family in care decisions. Due to the variety of medical monitoring and chronic medical conditions that can surround an individual with autism, the medical home model provides an appropriate context for health care.

What is a medical home?

Every individual deserves a medical home. In 2002, the American Academy of Pediatrics released a statement calling for a medical home for all children and youth with special health care needs. The AAP describes a medical home as a "model of delivering primary care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective."

In Washington State, medical home has evolved into the Patient-Centered Medical Home (PC-MH), providing comprehensive primary care for children, youth, and adults. The collaborative effort of the American Academy of Family Physicians, the AAP, the American College of Physicians, and the American Osteopathic Association established a set of principles to enhance patient-centered care (2007).

The groups recognized the value to all of a health care setting that facilitates partnerships between individual patients, families, personal physicians, and specialists for children and adults through the lifespan. To learn more about the Washington State Patient-Centered Medical Home, go to **www.medicalhome.org**.

Treatment Goals

The primary goals of treatment are to maximize an individual's ultimate functional independence and quality of life by minimizing the core autism spectrum disorder features, facilitating development and learning, promoting socialization, reducing maladaptive behaviors, and educating and supporting families (AAP, Clinical Report, Management of Children with Autism Spectrum Disorders, 2007) (see Appendix 11: American Academy of Pediatrics - Clinical Guidelines on Autism).

All treatments - medical and non-medical - should be reviewed at every visit. The frequency of this monitoring should be individualized to a person's specific needs. It includes monitoring an individual's progress, treating associated medical conditions, assisting the family in investigating and accessing appropriate medical and other interventions, and keeping the family informed about new medical tests and interventions. Adequate time should be allotted to address these issues.

Medical Areas to be Addressed

Accidental Injury

Increased rates of accidental injury can result from many of the more specific behavioral abnormalities. Social avoidance can cause excessive running. Sensory issues can cause ingestion of nonfood items or accidental burns and cuts. Absence of a sense of danger can place the individual in potentially harmful environments. Monitoring and preventive anticipation are important.

Aggression

While some degree of aggressive behavior is common in all children at various ages, children with ASD tend to express these behaviors more frequently and with greater intensity. Tantrums are common in young children with ASD. Oppositional Behavior is common in older children and adults. Tantrums can persist and elaborate into dangerous self-injury, aggression, and property destruction. Reasons for aggression are varied. Intervention is dependent on the suspected underlying triggers or causes (see Appendix 6: Functional Behavioral Assessment).

Anxiety

In addition to the impaired social interaction characteristic of ASD, some children will avoid social contact that results in high levels of anxiety (social anxiety). Generalized anxiety and anxiety secondary to interference with rituals or routine can also be problematic. Specific aversions (fears/phobias) can grow to debilitating proportions and prevent participation in formerly preferred activities. These anxiety disorders can respond to behavioral and/or pharmacologic treatment.

Attention Deficit/Hyperactivity Signs and Symptoms

Attention challenges in children with ASD can be manifested in poor discrimination learning, focusing on unusual or partial cues needed for an adaptive response, and rapidly shifting attention, which may be associated with increased general activity. Some children with ASD manifest more of these hyperactive and inattentive symptoms than others. Although attention-deficit hyperactivity disorder (ADHD) diagnostic criteria exclude the presence of autism, the target symptoms may sometimes respond to the same treatments as ADHD in the general population.

While 50 percent of children with ASD are reported to respond to medication management of "ADHD" symptoms, 20 percent could not tolerate methyphenidate. This rate is two times greater than typical peers (Reiersen, Todd, 2008).

Dental Care

According to American Academy of Pediatric Dentistry "Dental Home" guidelines, all children should be seen by a dentist for routine cleaning and evaluation by age one or within six months of the first tooth eruption. The same guideline holds true for children with ASD. Children with ASD are at increased risk for dental and gum disease due to damaging oral habits (such as the chewing of gravel or other hard material in pica; or tooth-grinding (bruxism); behavioral or seizure medications that reduce saliva flow or cause gum overgrowth; mouth breathing due to low oro-motor tone; trauma due to self-injuring behaviors, seizures or motor disorders; and physical abuse, to which children with disability are unfortunately at increased risk.

Children with autism often need general anesthesia to tolerate dental procedures. The treating dentist should have experience working with children with special needs, particularly if sedation is to be used.

Parents should strive to teach good dental hygiene at an early age since the sensory aversion associated with tooth brushing may make it difficult, if not impossible, to teach and implement brushing skills at an older age (see Appendix 13: Tips for Making an Oral Care Visit Successful for the Client with Autism).

Elopement (Wandering)

According to the Autism Society of America:

> It is important that your child has proper identification in the event that he or she runs away or gets lost and is unable to communicate effectively. Once a child with ASD becomes mobile, he or she may decide to walk out of the home without supervision. Children on the autism spectrum often like to be outside and in motion, so leaving the home to play outside is common. Once outside of the home, the child is then vulnerable and may be unable to get home or communicate where they live. If the child will tolerate wearing a medical ID bracelet or necklace, get one (they can be found at your local drug store).
>
> However, many children with autism do not like to wear jewelry, so the next best option is to place iron-on labels into each garment. Some children can be taught to carry and provide an identification card from a wallet or fanny pack and can learn to show their identification cards if they are not able to verbalize the information to another person. Some parents have also used specially designed tracking devises, perimeter systems, or service dogs for children on the spectrum who are known to elope.

Project Lifesaver is a reliable rapid-response active locating system relying on state of the art technology and a specially trained search and rescue team working in partnership with law enforcement to find individuals. People may enroll in the Project Lifesaver Program and wear a personalized bracelet that emits a tracking signal. When caregivers notify the local Project Lifesaver agency that the person is missing, a search and rescue team responds to the wanderer's area and starts a search with the mobile locators tracking system. Search times have been reduced from hours and days to minutes. In over 1,500 searches, there were no reports of serious injuries or deaths. Recovery times have averaged less than 30 minutes.

This program is active and administered in many counties in Washington through the local sheriff's office. Contact your county sheriff's headquarters for more information or visit the national Project Lifesaver web site at **www.projectlifesaver.org**.

Feeding/Nutrition

Individuals with ASD often display a limited variety of food preferences. This may be due to refusal to transition between textures, unwillingness to try foods of a particular color or texture, or difficulties related to mealtime. These food preferences may be a reflection of the rigidity with which many of the individuals function. Their parents perceive their food choices as unhealthy or too limited. With slow introduction of healthier food choices, the individuals can generally be encouraged to try new foods. Under-nutrition and overt malnutrition are rarely seen. A wide variety of dietary supplements and elimination diets are informally reported to improve or reduce many of the unfavorable behaviors seen in these individuals.

At this time, there are no conclusive scientific studies to support the use of these dietary interventions. Individuals with pica (eating non-edibles like rocks), coprophagia (feeding on feces) or obsessive-compulsive symptomatology manifesting as food or eating rituals should be referred for evaluation. Parents of children who experience these difficulties should consult with a professional (speech language pathologist, occupational therapist, psychologist, registered dietitian, nutritionist, behavior analyst etc.) who have experience working with feeding issues (e.g., skill deficits, behavioral feeding disorders etc.) in these children. For more information on feeding teams, go to: **http://depts.washington.edu/cshcnnut/** and learn more about the Western Maternal Child Health Nutrition Partners at: **www.mchnutritionpartners.ucla.edu/**.

Mood Disorder

Loss of interest in usual activities, unexplained fatigue, change in sleep habits (increase or decrease), change in appetite (increase or decrease), change in concentration or cognition, and signs of distress, such as moaning or crying for no apparent reason may reflect clinical depression. A person need not show all possible signs of depression to qualify for the diagnosis, but should have more than one.

The diagnosis should be especially suspected when a recent loss was sustained; although, because of their core deficits, persons with ASD may not appear as bereaved by death of a family member as would be expected and might be more affected by loss of an object. Decrease in sleep time, increase of activity level, unprovoked aggression, loss of inhibition (e.g., sexual), increased appetite, irritability, and giddiness or elation, especially if cyclical, may suggest bipolar disorder.

Again, a person need not show all signs and symptoms. Sometimes the main clue is a cycle of behavior of any kind (such as aggression, running away, self-injurious behavior), often preceded by a few nights of unaccustomed sleeplessness. All individuals with suspected mood disorders should be referred for further evaluation and treatment.

Obsessive/Compulsive and Severe Ritualistic Patterned Behavior

Compulsive behaviors and rituals are frequently seen in individuals with ASD. They can develop from narrow preferences or simple stereotypies (persistent repetition or sameness of acts, ideas or words). Excitement often accompanies ritualistic behavior. Attempts to obstruct or distract a person with ASD from pursuing patterned behavior may easily elicit explosive reactions or aggression, possibly anxiety-driven. When OCD (obsessive/compulsive disorder) features are present, they may respond favorably to appropriate behavioral or pharmacologic interventions or a combination of both. Atypical antipsychotics, such as Risperadone, are most typically used for this group of symptoms as well as for self-injurious behavior (ARP, 2007).

Puberty

Several issues occur during adolescence that may require assessment and monitoring. These include an increased incidence of epilepsy, especially complex partial seizures, mood disorders (depression and bipolar disorder), aggression, masturbation and increased interest in sexuality issues. Interventions are dependent on the underlying condition and include behavioral and pharmacologic treatment. Developmentally appropriate instruction about sexuality and issues such as menstruation and understanding of choices in areas such as birth control are important (see Chapter 6: Component 15 - Sexuality).

Psychiatric Disorders

The core diagnostic component of stereotyped, repetitive behavior and preoccupations, which can have obsessive-compulsive features, may be affected by drug intervention. In addition, individuals with ASD often develop associated or secondary psychopathology (emotional, mental, or behavioral) that may be responsive to treatment. The first line of treatment for most of these problems is behavioral; however in some cases, supplementation with medication is indicated (AAP, 2007).

Co-occurring psychiatric disorders are other medical conditions that are associated with and occur in this population at a higher rate than the general population. Estimates range from 28-78 percent, with approximately 45-55 percent of children with an autism spectrum disorder receiving psychotropic medication management (Ming, Brimacombe, Chaaban, Zimmerman-Bier, Wagner, 2008). Associated symptoms that are most typically targeted include irritability, lethargy, stereotypic behaviors, hyperactivity and atypical speech. While many children with ASD are responsive to medication management, careful monitoring is indicated due to intolerance.

Seizures

Children with ASD are at increased risk for the development of seizure disorders, with 20-30 percent or higher prevalence of epilepsy by adulthood among affected children with severe intellectual or motor disability (Persad, Thompson, Percy, 2005). The seizure prevalence is less than 10 percent among children with ASD who have less severe intellectual or motor impairments (Rapin, 1995). The types of seizures vary considerably, as is also seen in the non-autistic pediatric population. If children are exhibiting activity suggestive of seizures, they should have an EEG (Eltroencephalography measures brain electrical activity) (American Academy of Neurology, 2004).

There should be a low threshold for obtaining an EEG on children who are exhibiting activity suggestive of seizures. Importantly, non-specific EEG changes are quite common in children with ASD across the range of intellectual or motor impairment, and often cannot be clearly interpreted. Treatment with anticonvulsant medication depends on the seizure type and frequency, with close monitoring by a pediatric neurologist during medication initiation, titration and switches.

Self-Injurious Behavior

Self-injurious behavior (SIB), such as head banging, picking, biting, and self-hitting, occur in individuals with ASD, especially those with mental retardation and impaired communication ability. Investigation of potential triggers or causation is mandatory. Intervention may be behavioral and or pharmacologic, depending on the suspected underlying reason.

Sensory Issues

Many children with ASD show differences in their responses to various sensory stimuli. They may have increased or decreased awareness to a particular stimulus. Sensory issues may contribute to problematic behavior. At times, stimulus sensitivity may be a manifestation of an underlying condition such as anxiety mood disorder and will improve with treatment of the condition. While anecdotal reports of benefit from specific interventions such as sensory integration therapy or a "sensory diet" are widespread, available study results are limited by the small sample size and further research is warranted (see Chapter 5: Essential Components of Instruction and Chapter 6: Essential Component 9 - Sensory Motor Processing).

Sleep

Sleep difficulties are quite common in individuals with ASD, occurring in 75-95 percent of diagnosed cases (Ming, Brimacombe, Chaaban, Zimmerman-Bier, Wagner, 2008). Problems in sleep onset, night waking, and early waking are particularly frequent, and may reflect behavioral and or underlying "organic" origins. Consequences of sleep problems can include a disrupted family life, poorer learning and memory for the child, and making aggression and other undesired behaviors worse. Therefore, sleep disturbance should be addressed firmly.

Behavioral strategies to ensure good sleep hygiene should be established. A medical workup might be indicated. Consult with the individual's health care provider about the use of medications, including complementary medication such as melatonin. Since seizures can disrupt sleep and insufficient sleep can trigger seizures in pre-disposed children, an EEG should be considered in the appropriate context.

Stereotypies

Defined as persistent repetition or sameness of acts, ideas or words, stereotypie behavior characterizes much of the play of young children with ASD. This can consist of looking at bright objects, listening to repeated sounds and vocalizations or repetitive motor mannerisms. High rates of stereotypies can interfere with adaptive learning in school and in the community. Stereotypies may persist into adulthood. They are more common and refractory in people with ASD and multiple, often undiagnosed, sensory deficits, and in those with greater degrees of intellectual disability. The behaviors are often unresponsive to medication.

Tics

Tics are irregular, stereotyped, repetitive muscular contractions which may mimic apparently meaningful behavior. Tics vary greatly in frequency, intensity, complexity of expression, and body location. Some clinicians report a greater-than-chance co-occurrence of tics and Asperger Disorder or PDD-NOS. Mild non-impairing tics need not be treated. Tics are seldom so severe as to cause functional impairment or physical damage, for which medication is usually indicated. In higher cognitively functioning children, behavioral interventions specifically designed to reduce tics may be effective.

Medications

Like any treatment, medications should be reviewed at every follow-up visit. A variety of medications have been described for individuals with ASD and several have been researched. However, there is no one medication that works for every person with ASD. The medication treatment of an individual with ASD needs to be symptom specific. Hyperactivity, sleep problems, obsessive tendencies, anxiety, aggression, and self-injury are some of the symptoms that may be targeted with specific medications. Often, a single medication will target several symptoms, which can be desirable when working to minimize the number of medications a child is prescribed.

Medications should be given on a trial basis with close monitoring of positive and negative effects. Since there are few objective measures of a person's response to a medication, reliance on subjective information (parent, teacher and caregiver reports) is common. The observations of parents and caregivers should be systematically collected by logs, charts, scales, or other accepted behavioral documentation. A trial of medication tapering and discontinuation should be undertaken periodically, under close professional guidance, to determine its efficacy and whether it is still needed.

Alternative and Complementary Intervention

Interventions have been proposed based on theories of autism causation such as heavy metal poisoning, dietary factors, and auditory hypersensitivity. A growing range of insufficiently assessed interventions challenge families and providers to find a meaningful and appropriate balance in management that considers safety and efficacy while respecting parents' rights to pursue help for their affected children in a manner consistent with their values and imperatives. Broadly, complementary or alternative (CAM) approaches may be divided into "biomedical" and "non-biomedical" groupings, the latter of which include educational, behavioral and other therapeutic strategies.

While anecdotal reports of intervention efficacy exist for most popular CAM modalities explored in the treatment of ASD, by definition CAMs have inadequate reproducible scientific research to support confident statements of efficacy or safety; however, the potential benefit for any approach, including but not limited to "placebo effect," may be very real. If a CAM trial is undertaken for a child, one should consider all available information regarding safety and efficacy to ensure that the chosen intervention will not impede the implementation, safety or efficacy of other tested treatments (see Appendix 10: Choosing Treatment Options).

Chapter 5: Essential Components of Instruction

Considerations

This section describes different components of instruction that should be addressed with individuals with Autism Spectrum Disorder (ASD) from kindergarten through high school. It includes an explanation of the unique learning styles of individuals with ASD and considerations for creating effective learning environments. Though this section speaks specifically to education beginning in Kindergarten, early intervention is the key to success. For more information, refer to Appendix 2: Early Intervention - Birth to Age 3 and Appendix 3: Special Education - Three Through Five.

This section is best used in conjunction with the rest of the document because it offers strategies to address skills that form the foundation for learning and underlie all other areas, e.g., attention, imitation. It incorporates the information from the other sections and applies that information to teaching situations, gives specific techniques to address the other areas, and is intended to work within the general curriculum (see Appendix 9: Implications for the Education System).

Along with this Guidebook, other organizations have helpful guides to assist teachers and parents in understanding autism. These include *The Puzzle of Autism* by the National Education Association (NEA, 2006), and *The Educational Aspects of Autism Spectrum Disorders Manual*, from The Office of the Superintendent of Public Instruction (OSPI) in partnership with the Autism Outreach Project of Washington State.

The NEA states:

> The number of children diagnosed as having autism has increased substantially and many of these students are in general education classrooms. How can general education teachers and other education professionals address their complex communication, social and learning needs? To assist educators in their daily work, NEA has produced a new resource in collaboration with the Autism Society of America, the American Speech-Language-Hearing Association, and the National Association of School Psychologists.

The Puzzle of Autism is a brief and clear informational guide for all education personnel who work with students with ASD. The guide explains common autistic characteristics and suggests effective classroom strategies for improving the communication, sensory, social, and behavioral skills of children who have autism. *The Puzzle of Autism* is available online at **www.nea.org/assets/docs/autismpuzzle.pdf**.

Washington's OSPI publication, *The Educational Aspects of Autism Spectrum Disorders Manual* (2003), provides information about educating students with ASD and is beneficial to parents, teachers, speech-language pathologists, school psychologists, and others involved in educational planning for children on the spectrum. It is available in school district offices or online at **www.k12.wa.us/SpecialEd/pubdocs/Autism%20Manual.pdf**.

There are numerous methods and instructional strategies that are specifically designed for use with individuals with ASD. Professionals may incorporate a variety of approaches into instruction, but it is critical that the method or strategy be:

- Matched to the strengths and needs of the individuals
- Modified as individuals change
- Effective in supporting independence and learning

Learning Styles of Individuals With ASD

Individuals with ASD have the capacity to learn a variety of concepts and skills. However, because of unique communication and sensory motor processing issues, it is critical that instruction is designed with their individual learning styles in mind. Learning styles are based on:

Individual Strengths: Individuals with ASD exhibit varied cognitive strengths and challenges (e.g., visual, auditory memory, spatial, kinesthetic). Careful assessment should be integrated to identify an individual's unique profile to tailor instruction and accommodations.

Individual Interests: Individuals with ASD may focus on specific topics of interest. This focus may allow them to develop a unique perspective, a specific skill, or a depth of understanding; therefore, it is important to support and expand areas of interest and not extinguish them. Indeed, these interests can lead to meaningful leisure activities and employment outcomes.

Individual Motivators: These motivators come from every person's need to derive reward for pursuits and interactions. Teachers, through instruction, build in assumptions of successful motivators such as grades, praise, stickers, etc. It is important to identify, with the help of family and the individual, the motivators that will provide incentives toward learning. Individuals with ASD often have unusual motivators that include completion of tasks, sensory-based stimuli, special interests, tactile-based stimuli, pace of activity, etc. Teachers need to understand and tolerate motivators that will not inhibit the learning environment.

Communication Style: Individuals with ASD have unique abilities and difficulties with regards to communication and language. The communication process can be made difficult because professionals may assume individuals do not understand and then make conclusions based on individual input or non-input. In teaching, individuals must communicate back understanding to the teacher. Teachers who are most effective in the communication process use multiple strategies simultaneously such as visual, auditory, written, symbolic, etc.

Sensory Motor Processing: Sensory motor proficiency involves the taking in of information from one's body and the environment through a variety of sensory channels, interpreting and understanding these sensations, and developing a response to them. Sensory systems include auditory, visual, tactile, proprioceptive, vestibular, olfactory, and gustatory. Individuals with ASD may rely heavily on one or two sensory channels to compensate for deficits in other modalities. Preferences for specific sensory systems may therefore result in learning styles that are different from typically-developing peers. For example, individuals may need to pair a motor activity with learning new material such as isometric exercises paired with multiplication tables.

Pattern of Skill Development: The premise of instruction is to teach in a sequential pattern of skill development. Individuals with ASD may have highly developed skills in one area and be delayed in others. Professionals should not assume that with a highly developed skill there are not gaps in learning. Teachers may need to teach holistically rather than sequential levels. Learning need not be linear to be understood.

Social Understanding: This is the ability of the individual to read social cues and the context and behave accordingly. Typically, social situations for individuals with ASD are often very stressful. Teaching techniques that rely on social situations may cause stress in individuals with ASD because of the reliance on social relationships. Individuals may have an inability to participate appropriately in the context of class discussions.

In conclusion, instructional strategies should be based on individual learning styles and should take into consideration and capitalize upon the aspects of unique learning styles.

Purpose of Assessment

The purpose of assessment is to develop instruction appropriate to the needs of each individual. ASD is considered to be a triad of impairments with core deficits in socialization, communication and behavior. It is critical that the assessment and evaluation process reflect those three core areas of deficit. Federal and state guidelines (Washington Administrative Code [WAC] 392-172A-03020 and *The Educational Aspects of Autism Spectrum Disorders Manual*, 2008) require assessment in the following domains:

- Cognitive
- Social/Emotional
- Academics
- Communication
- Vocational/Occupational
- Adaptive Behavior

However, assessments of individuals with ASD must also address areas of strengths, interests, and sensory motor abilities in order to get valid information on which to base instructional strategies. Emphasis on these additional areas will facilitate the assessment process itself and provide critical information for developing the individual's learning.

Assessments, whether ongoing or part of an evaluation need to take into consideration the unique learning style of the person with ASD. Assessments and evaluations should include information from the parent(s); data from previous interventions; criterion-referenced assessments; curriculum-based assessments; standardized, norm-referenced tests; structured interviews; and structured observations. On the other hand, most norm-referenced tests have limited usefulness in curriculum development. Regardless of the tools used, person(s) conducting the assessment must have a firm understanding of autism in order for the results to be valid.

Elements that will help to optimize the results of the assessment process include previous familiarity with the individual, shorter test periods over multiple sessions, advance notice to the individual prior to testing, and sensory motor preparation for an optimum level of alertness. An additional resource for both educators and parents can be found in Appendix 8: Educational Best Practice Guidelines Check List.

Aspects of a Learning Environment

Any instruction must include a carefully planned environment that is predictable, structured and appropriate for the sensory motor needs of the individual. Environments, including the regular classroom, resource room, community, and home, can be engineered to support the degree and type of structure that the individual requires.

Learning and behavior may be enhanced by physical space modifications that include visual barriers, reduced visual or sound distractions, temperature adjustments, preferential seating, and visual organization of material.

One methodology that can be utilized to enhance the level of structure and predictability within an environment is the TEACCH system (Treatment and Education of Autistic and Related Communication-handicapped Children). TEACCH was developed in the early 1970s by Eric Schopler at the University of North Carolina in Chapel Hill. The TEACCH program's position states that to effectively teach students with autism, a teacher must provide structure, i.e., set up the classroom so that students understand where to be, what to do, and how to do it, all as independently as possible. The methodology utilizes physical and environmental structure, scheduling, and structured work tasks and sessions to help persons with ASD become more successful and independent (see Appendix 4: Least Restrictive Environment and Natural Environment and Appendix 7: Instructional Accommodations and Modifications).

Focus of Interventions – All Ages

Federal law (IDEA, 2004) requires that, to the fullest extent possible, all individuals have access to, and make progress in, the general curriculum; however, the instruction must be meaningful, purposeful, and age appropriate for the individual. The individual with ASD will have specific goals and objectives that need to be addressed in order to participate and progress in the general education curriculum.

Particular attention needs to be paid to the following areas to increase the individual's ability to benefit from the educational experience and become more competent and independent adults.

Attention

Purpose—Increase awareness of others, develop appropriate learning processes, establish attention to critical task stimuli, and reduce over-selective attention.

Target Areas:

a. Acknowledgment of external world
b. Sustained attention (attending on a regular basis)
c. Saliency (looking at what is important)
d. Joint attention (attending with people)
e. Attention shifting (flexibility in attending) event to event, object to object, object to person, and person to object

Imitation

Purpose—Prepare for learning complex skills, enable observational learning from peers and build reciprocal interaction.

Target Areas:

a. Pre-requisite to imitative learning is that it must be purposeful and independent.
b. Attention to model: imitation of movements, vocalizations, verbalizations, and gestures.

Communication

Purpose—Establish verbal or augmented communication skills; enhance social interaction as an initiator and responder; enhance comprehension of events and persons in the environment; provide appropriate alternatives to challenging behaviors by teaching a functional communication system.

Target Areas:

a. Use and comprehend nonverbal communication (gestures, gaze, and facial postures).
b. Use and comprehend nonverbal communication and primary vocabulary and simple sentence structures.
c. Use and comprehend nonverbal communication and vocabulary and simple sentence structures and grammatical parts of speech.

d. Use and comprehend combined/multiple communicative means.
e. Use communicative means for a variety of reasons (request, protest, comment, repair, etc.).
f. Use echolalia functionally.
g. Increase use of spontaneous language.
h. Continue vocabulary building, comprehension and use.
i. Develop effective means to communicate needs, wants, desires, and emotions.

Socialization

Purpose—Establish social and affective contact with others.

Target Areas:

a. Intentional and systematic introduction to social situations with initiation and respondent acts.
b. Turn-taking – including non-verbal/vocal/verbal turns.
c. Adult-child and child-child interactions.
d. Sharing with others.
e. Ability to give help and accept help.
f. Choice-making.
g. Understanding other person's emotions and perspectives.
h. Interdependence – be able to assist and accept assistance from others.
i. Sense of belonging: as a son or daughter, sibling, student, or co-worker.
i. Development of a repertoire of expected social behaviors for environments where the individual lives, learns, works, and spends leisure time.
j. Development of skills and abilities which lead to positive interactions and relationships.

Cognition

Purpose—Enhance conceptual, problem-solving, and academic performance and executive function (flexible, strategic plan of action to solve a problem or attain a future goal).

Target Areas:

a. Utilization of multiple modes of learning concepts and skills (e.g., sorting, matching, classifying, problem-solving, categorizing, comparisons, ordinals, sequencing, temporal understanding, spatial understanding)
b. Understanding cause and effect
c. Abstract thinking
d. Humor

Purposeful Play / Recreation / Leisure / Physical Exercise

Purpose—Enhance cognitive, social and motor skills; enhance relationships between self and environment; shape appropriate use of unstructured time; increase opportunities to get physical exercise and stay healthy; increase enjoyment of life.

Target Areas:

a. Intentional and systematic introduction of a variety of play and leisure skills.
b. Interaction/cooperation with peers.
c. Leisure skill building to include toys, games, hobbies, sports, creative arts (drama, music, writing, arts and crafts).
d. Recreation and physical exercise to include walking, hiking, team and individual sports, and other activities that promote good health and decrease obesity and chronic health conditions.

Self-Determination

Purpose—Enhance the individual's ability/opportunity to make executive function decisions (choices and options) through means of communication, relationship and visual organization; foods, clothing, activities, employment, residential, roommates, etc. Choices are limited to people's experience; broaden the experience, record outcomes, and review visually with the individual his/her experiences to develop choice.

Target Area:

Intentional and systematic instruction of sequencing, categorizing, and communicating preferences.

Essential Life Skills

Purpose—Increase personal independence and create opportunities for greater community participation including independent living, working and recreating.

Target Areas:

a. Transitioning within daily activities
b. Self-help: e.g., toileting, dressing-undressing, eating, feeding, and drinking
c. Safety and ability to say "no"
d. Hygiene
e. Gross and fine motor coordination
f. Managing sensory stimuli
g. Purposeful communication
h. Productivity of a task
i. Flexibility of a task
j. Communication
k. Self-determination, self-advocacy, choice
l. Navigating public transportation system(s)

Transition

Purpose—Facilitate integration of the individual into the community in terms of work or post-secondary education, recreation, and residence.

Target Areas:

a. Generalization of learned skills and strategies to the next environment.
b. Exploration of areas of interest or strength.
c. Selection of community options including work, leisure, residence, and post-secondary activities.

Sexuality (as determined by student's team to be developmentally appropriate)

Purpose—Assist the individual to understand and express sexuality in an acceptable and appropriate manner.

Target Areas:

a. Acquire skills which assist in the development of friendship.
b. Develop personal health and hygiene.
c. Understand changes in the body and how to manage the changes.
d. Develop specific and appropriate outlets to express sexuality.

Behavior

Purpose—Develop functional behaviors that are acceptable in the school, work, and community environments.

Target Areas:

a. Develop effective means to communicate needs, wants, desires, and emotions.
b. Develop skills and abilities which lead to positive and acceptable behaviors.

Description of Teaching Strategies and Methodologies That Are Data Driven

Teaching strategies need to be based on peer reviewed and empirically validated evidence-based practices and methodologies for students with autism. At this time the science heavily favors, but is not limited to, those based on the science of applied behavior analysis, defined as the application of behavioral principles for the benefit of the learner and includes simultaneous evaluation of the effect of these applications.

The following section (taken from the Ohio Parent Guide) summarizes evidence-based practices that should be considered when developing instructional programs for students on the autism spectrum.

Applied Behavior Analysis

Applied behavior analysis (ABA) is the scientific study of the principles of human behavior. The Florida Department of Children and Families defines ABA as:

> The design, implementation, and evaluation of systematic environmental modifications for the purpose of producing socially significant improvements in and understanding of human behavior based on the principles of behavior identified through the experimental analysis of behavior. (**www.abatherapy.net**)

ABA includes finding out the connection between an individual's behavior and his or her environment. In other words, what is causing the behavior? ABA uses direct observation and measurement of behavior and environment. Measurement looks at how often, what time, how long, to whom, or how intensely a behavior occurs. ABA also looks at what happens in or to the environment right before a behavior occurs, otherwise known as the antecedent behavior. Antecedent behavior includes verbal, gestural or physical prompts, cues, materials, language, and environmental factors (sensory input: noise, light, smell, taste, touch), either naturally occurring or intentionally manipulated to affect a behavior.

The consequence of the behavior is what occurs after the behavior. Consequences include reinforcement, both positive and negative, and punishment. Reinforcement increases the likelihood of the behavior occurring again. Punishment procedures increase the likelihood of the behavior diminishing or disappearing (known as extinction). The sequence of ABA is sometimes referred to as ABC: antecedent, behavior, consequence.

A substantial amount of research has shown that ABA can be effective for children with ASD.

Comprehensive Autism Planning System (CAPS)

This comprehensive, yet easy-to-use system allows educators to understand how and when to implement an instructional program for students with autism spectrum disorders (ASD). The CAPS model answers the questions (a) What supports does my student/child need in each class to be successful? (b) What goals is my student/child working on? and (c) Is there a thoughtful sequence to the student's/child's day that matches his learning style. This timely resource addresses adequate yearly progress (AYP), response to intervention (RTI), and positive behavior support (PBS) in a common-sense format. The CAPS process

was designed to be used by the child's educational team, consisting of parents, general educators, special educators, paraprofessionals, speech-language pathologists, occupational therapists, physical therapists, administrators, psychologists, consultants, siblings, and others who are stakeholders in the student's education.

The structure of this innovative tool ensures consistent use of supports to ensure student success as well as data collection to measure that success.

In addition, CAPS fosters targeted professional development. Because CAPS identifies supports for each of the student's daily activities, it is possible for all educational professionals working with the student to readily identify the methods, supports, and structures in which they themselves need training (Henry, Smith Myles, 2007).

Discrete Trial Training

ABA is not synonymous with discrete trial training (DTT), although many erroneously use the terms interchangeably. DTT is an ABA strategy. DTT is a distinct and complete behavioral event that includes a discriminative stimulus or the antecedent (what happens before the behavior), the response or behavior (what the child is required to do), and the consequence for the behavior (reinforcement). The term "Lovaas Therapy" comes from Dr. O. Ivar Lovaas, whose landmark research led to the application of DTT techniques to teach children with autism.

Social Thinking

Simply put, social thinking is our innate ability to think through and apply information to succeed in situations that require social knowledge. Social thinking is a form of intelligence that is key to learning concepts and integrating information across a variety of settings: academic, social, home, and community. Limited abilities for learning and or applying socially relevant information can be considered a social thinking learning disability. The great difficulty encountered when trying to determine if a child has social thinking challenges is that standardized tests available through educational, psychological and or speech and language evaluations fail to reveal problems in this area.

Thus a child's ability to do well on testing in no way proves or disproves the possibility that he or she may have a significant learning disability in the form of social thinking. The reason that standardized tests lack in their ability to illuminate deficits in this area is that testing needs to be highly structured in order to cleanly measure the very specific skills that the test or subtest was designed to evaluate. However, social cognition requires the complex integration of multiple skills. Thus, standardized test formats, as written today, are often counter to the evaluation process for exploring social thinking skills.

Social thinking challenges represent a social executive function problem. The ability to socially process and respond to information requires more than factual knowledge of the rules of social interaction. It also requires the ability to consider the perspective of the person with whom you are speaking. Perspective taking can be defined as considering the emotions, thoughts, beliefs, prior knowledge, motives and intentions of the person with whom one is communicating as well as one's self.

This ability then allows one to not only better determine the actual meaning behind the message being communicated but also how best to respond to that message. Thus applying social knowledge and related social skills successfully during social interactions requires the complex synchronicity of perspective taking along with language processing, visual interpretation and the ability to formulate a related response (verbal or non-verbal) in a very short period of time (1-3 seconds).

Finally, social thinking challenges do not only reveal themselves during social interactions, but instead they are present during many academic tasks that require highly flexible abstract thinking such as written expression, reading comprehension of literature, organization, and planning of assignments. Some students have tremendous difficulty learning math skills. Thus persons with significant difficulties relating to others interpersonally often have related academic struggles in the classroom particularly as they get older.

Typically, we start to require more creative thinking, flexibility, and organizational skills to succeed in the classroom curriculum starting in 3rd to 4th grade. Some students begin to show struggles at that time, while others students manage to hold it together until middle school. It is very common for students to develop academic problems only when they get older even when it is determined that this person is "quite bright" according to psycho-educational measures.

TEACCH

Developed in the early 1970s by Eric Schopler, the TEACCH (Treatment and Education of Autistic and Related Communication-handicapped Children) approach focuses on the person with autism and designing a program around his/her skills, interests, and needs. Thus, the individual, rather than the instructional method, is the priority.

The program uses structured teaching in a variety of settings. Organizing the physical environment, developing schedules and work systems, making expectations clear and explicit, and using visual materials have been found to be effective ways of developing skills and allowing people with ASD to use these skills independent of direct adult prompting and cueing.

Cultivating strengths and interests, rather than drilling solely on deficits, is another important priority. The relative strengths of those with autism in visual skills, recognizing details, and memory, among other areas, can become the basis of successful adult functioning (Mesibov & Shea, 2006).

Communication

Communication difficulties, both verbal and nonverbal, are inherent in the diagnosis of ASD. The typical sequence of communication development is disrupted. As a result, communication skills can range from nonverbal, gestural and the use of single words, to verbal conversation, and may include:

- Perseveration - repetitive verbal and physical behaviors.
- Echolalia - immediate and/or delayed "echoing" of words, music, phrases or sentences.
- Hyperlexia - precocious knowledge of letters and words or a highly developed ability to recognize words but without full comprehension.
- Dactolalia - repetition of signs, pronoun reversals, inappropriate responses to yes or no questions, and difficulty responding to "wh" questions.

When designing intervention strategies, it is important to understand both the individual's receptive (comprehensive) and expressive communication skills. Stressful situations that increase anxiety often interfere with the ability to communicate. Difficulty understanding humor, idioms ("keep your eye on the paper"), sarcasm, and other complex forms of verbal and written expression is common. Even the highly verbal individual may understand and use literal (concrete) language, but have difficulty with abstract concepts needed for higher order thinking skills.

A person's communication ability usually changes over time. Therefore, it is important to maintain an ongoing communication assessment from diagnosis through adulthood as this provides current information, which is necessary to support appropriate communication strategies.

Supporting all forms of communication – verbal, signing, pictorial, augmentative devices (and often a combination of more than one) – promotes learning.

Common Communication Options

Sign Language
Use of signs alone or paired with speech.

Picture Exchange Communication System (PECS)
Involves using picture symbols to communicate wants/needs, label and so on. The child goes through a learning process that teaches initiation of communication and then expands to the use of sentences. Many children who use PECS develop some verbal skills and may graduate to speech as the primary form of communication.

Communication Boards
Can be made with pictures of objects that the child points to or removes from the board to communicate wants/needs.

Other Communication Devices
A wide range of devices designed to enable the user to create longer messages. These devices can also act as a universal remote, allowing the user to operate electronic devices in the environment such as the TV, lights, and so on. The speech-language therapist can assess the child's abilities to use high-technology devices and make recommendations about the type of device best suited for the individual's needs.

Total Communication
A communication system that pairs simultaneous production of speech with manual signs or another augmentative devices or symbol systems. The child is encouraged to use the word or phrase that he is capable of producing and supplementing communication with signs, symbols, and so on, for what he cannot communicate verbally.

Chapter 6: Essential Components of an Instructional Program

In recent years, professionals and families were presented with encouraging data and reports of successful interventions for individuals with ASD. Although research documents a number of programs demonstrating substantial benefits for individuals with ASD, differences exist in reference to funding, location, degree of family and community involvement, available resources, and program content and structure.

The purpose of the following section is to provide educators, administrators, individuals, and families with a framework and structure for program development and evaluation. As noted in this unit's "Key Areas," there are a variety of essential components.

Sixteen Essential Components:

- **Family Involvement**
- **Earliest intervention**
- **Intensity**
- **Predictability and Structure**
- **Generalization of Skills**
- **Functional Analysis of Behaviors**
- **Communication**
- **Assistive Technology**
- **Sensory Motor Processing**
- **Social, Emotional, and Sensory Regulation**
- **Social Development**
- **Inclusion with Typically Developing Peers**
- **Progress Monitoring**
- **Supported Transitions Across Multiple Environments**
- **Sexuality**
- **Lifelong Support**

Essential Component 1: Family Involvement

This section describes the importance of collaboration between families, individuals on the spectrum, medical and educational professionals, and the community. It includes guidelines for ensuring high-quality communication between families and others that are invested in the success of the individual with ASD. The Family Involvement section is best used in conjunction with the rest of this document. Just as the family cannot be isolated from the various aspects of their child's life, this section of the document, which addresses family participation, must be considered with all other portions of the document.

The family is the most important part of a person's life from infancy throughout adulthood. It is within the family context that the individual receives the most support and develops the skills to relate to others beyond the family. Although both families and professionals expect individuals to meet current and future goals, it is the family who will ensure consistent commitment to an individual over time.

Families, educational staff, medical professionals, first responders, state and local agency officials and community members share the responsibility of meeting the needs of an individual with ASD. There must be ongoing collaboration and communication with family members, professionals and community members. Optimally, it is a partnership where everyone's contributions are valued and respected. Families and professionals bring to the team their own perspectives, responsibilities and strengths.

Each team member should begin the planning process with the same general mission to promote the independence and satisfaction of the individual to the extent possible throughout life's transitions, e.g.: to have a purposeful job, a home, friends, and a sense of social belonging. While each team member may bring important pieces of the planning puzzle to the table, incorporating the pieces into a comprehensive plan requires the collective cooperation of all team members. Because of the intense challenge of those with ASD, it is more advantageous for all parties to freely and openly share these challenges and barriers to assure the most creative outcomes.

Communication between home and school is critical.

As the individual with ASD gets older, aspects of family and school communication will evolve. To the extent that the individual is able, he or she needs to be included in all discussions regarding their plan, e.g.: transition process, teaching priorities, etc. As siblings get older, they can be involved at the level they feel comfortable. Often a sibling attends the same school and can lend a unique perspective to the partnership. Peers of the individual may also offer valuable insight and support to the planning process and to the individual's well being.

Throughout life transitions, there are many direct service staff and professionals who will come and go as part of the individual's team. The family's role is a constant through much of the individual's life and may represent stability during the changes. Families vary greatly in their ability to meet an individual's needs because of the differing resources they have. Even when an individual receives educational services in a school building, much programming may still need to occur at home. Therefore, the roles and responsibilities of family members, schools, and professionals are ever changing and evolve over time.

Many individuals with ASD are not reliable communicators, so families may struggle to know what went on in other settings. Conversely, teachers and other service providers often lack input about the home setting that affects the individual during the school day. Some families hire people to work with the individual at home using funding made available to them through government sources (such as Medicaid Personal Care) as well as their own resources.

Others coordinate the services but leave the direct program design and implementation to others. Families and professionals should engage in ongoing meaningful communication about the individual and the services being received in order to broker the right supports in the best way to fit the individual and the plan.

The following are guidelines for providing family and professional collaboration:

Effective Communication

- Families and professionals should display mutual respect, keeping the focus on the individual and his or her strengths, choices, and needs. Communication should be kept respectful, candid, confidential, and constructive.
- Families and professionals should explore options about how communication channels can best be kept open between home, school, medical, and other outside program settings. These options will vary depending on the ability of the individual with ASD to communicate and his or her age. Commonly used methods include notebooks passed back and forth, home visits, phone calls, e-mail, and scheduled visits to the school by parents or caregivers.
- Families and professionals should frequently share successes, progress, and strengths of the individual with ASD, as well as problems and deficits.

Team Process

- Families as well as the individual should always be active members of the multidisciplinary team. The individual's wishes and desires should be considered as part of the self-determination process. Self-determination is defined as a combination of skills, knowledge, and beliefs that enable a person to engage in goal-directed, self-regulated, autonomous behavior.
- Families should share their hopes and dreams for their children with the professionals who share their lives (e.g., use of the vision statement on the IEP). Families should be given the opportunity to collaborate in the designing of the individual's program, including through the IEP process (see Appendix 8: Education Best Practice Guideline Checklist). At the age of sixteen, this will include transition planning as well.
- Because individuals with ASD typically require lengthy planning and training for transitioning from school to work, the transition visioning process should be encouraged before age sixteen.
- Families should be an integral part of the ongoing assessment of the effectiveness of the individual's program and in any modifications that will be needed.

Information and Advocacy

Advocacy by parents and family members is essential to ensure that children with ASD have an opportunity to achieve their fullest potential. As important as professionals are in furthering the knowledge of individuals with ASD and meeting their needs, parents and family members have a critical role of educating professionals and policy makers. Parents evolve from the first encounter of the concept of ASD. Families and parents need a great deal of information and support to become educated and able to provide support and information to others. Because everyone enjoys the opportunity to talk about what is important personally, parents are natural advocates as they talk with other parents about experiences (see Chapter 10: Advocacy).

Essential Component 2: Earliest Intervention

The standard "earlier is better" may serve as a particular advantage for children with ASD (Lovaas, 1987; McClannahan & Krantz, 1993). However, identifying and diagnosing ASD at any age allows professionals and families to address the challenges associated with ASD and develop an effective program.

Most educators and families agree with the position that intervention programs are more effective when begun at the earliest age possible.

Services provided in these programs achieve the following outcomes for individuals with ASD and their families:

- Provide the opportunity to intervene to minimize the development of interfering behaviors and secondary disabilities.
- Facilitate gains in attention, imitation, communication, socialization, cognition, leisure skills, work skills and other essential life skills.
- Help support the development of a young person with ASD, establish social networks, and reduce family stress.
- Increase independence and decrease likelihood of social dependence.
- Teach functional communication strategies.
- Reduce societal costs for services that will be needed later in life.

- Include the individual with ASD and the family in intervention planning and implementation to promote generalization and maintenance of skills.

Essential Component 3: Intensity

Although the duration of intervention (e.g., number of hours per day or per week) and number of contexts (e.g., home, school, community) encourages the debate of what constitutes sufficient intensity, what is agreed upon is that more intense quality intervention generally results in better outcomes and that the intensity of interventions is determined by the unique needs of each family and individual.

The following general suggestions may be used to guide decision-making:

- Assess the individual's needs for year round intervention programming across contexts.
- Assess the need for individual vs. group programming.
- Focus on assessment-driven individualized programming and instruction.
- Assess the individual's and family's strengths and needs in regards to programming.
- Stress ongoing support and staff development of teachers, support staff, and related services working with individuals with ASD.
- Provide individuals with ASD continuity of programming across people and settings as agreed upon in the Individualized Education Plan (IEP) or Individualized Family Service Plan (IFSP).
- Recognize that effective intervention for ASD requires ongoing assessment and ongoing individualized programming.

Essential Component 4: Predictability and Structure

Individuals with ASD benefit from an environment that incorporates a structured program tailored to meet their individualized needs. A thorough structure also enables professionals to stay in tune with daily events that may create stressful situations for the individual. Professionals and families need to collaborate to develop effective goals and objectives to create an environment that promotes continuity, cohesion and consistency to best meet individual needs and enhance their independence. Uniform and comprehensive training of these transdisciplinary teams needs to be ongoing and consistent to support successful educational programming.

To provide the necessary organization in the educational setting, the following components are critical when providing predictability and structure:

Teaching the concept of "Time" and the Passage of Time

- Use calendars.
- Create visual daily schedules (to prepare in advance for regular and unexpected changes in routine).
- Use an analog clock to pair routines, activities, and transitions.

The functional and organizational layout of the environment

- Provide a safe environment (e.g., adult/child-individual ratio, exit doors).
- Visually identify all areas of the room (using pictures and/or words).
- Use natural boundaries, such as desks, files, and partitions, to create specific areas.
- Clearly define and visually represent "Rules of the Room".
- Use environmental modifications to help manage and tolerate sensory stimuli.

Utilize materials that enhance play, leisure, academic and vocational activities

- Use hands-on materials and manipulatives.
- Use assistive technology (computers, augmentative devices, switches, assistive listening devices, calculators, etc.).
- Use multiple modalities (e.g., visual, auditory, tactile) and methodologies to provide information and structure.

Teaching social skills to develop environmental awareness

- Clearly define and visually represent "Rules of the Room."
- Provide social awareness using social skill development activities.
- Teach how to read "body language" and gestures.
- Teach the understanding of empathy and humor.
- Recognize emotions and situations where emotions are expressed.

Essential Component 5: Generalization of Skills

Typically, young individuals will learn incidentally from the activities and persons in their environment and will generalize these observed skills with minimal effort. For individuals with ASD, however, it is difficult to utilize a learned or observed skill in another setting. They do not necessarily model or imitate observed behaviors and may not understand that a "skill" learned in isolation can and should be generalized in other environments. For this reason, programming for appropriate generalized outcomes has long been recognized as a critical component of interventions for individuals with ASD.

The need for generalization should be considered across a variety of circumstances, e.g., across time, settings, persons, and behaviors. Time refers to maintaining the use of a learned skill after the teaching process has stopped. Across settings refers to the use of a learned skill in settings outside the teaching environment. Persons refer to the use of a learned skill with and without the individual who taught the skill and that the skill can be demonstrated with others. Generalization across behaviors refers to changes in untaught skills which are related to the skill being taught, e.g., teaching an individual to say "Hi" not only increases the use of that word upon greeting someone, but also increases other greeting behaviors such as waving, making eye contact, etc., which are not being directly taught.

These forms of generalization all need to be considered in any program designed to teach new skills to an individual with ASD and specific strategies to promote generalization need to be incorporated into the teaching process.

Some individuals, however, may over-generalize, which is an over-application of a concept (product of over-selectivity). For example, if they determine that the critical feature of an animal is four legs and are not identifying with the other features, then the individual will assume that all four-legged creatures are the same animal.

The following are a number of teaching strategies to assist in fostering generalization:

- Skills taught in an instructional environment should lead to naturally occurring, positively rewarding consequences in everyday environments. For example: learning to make a peanut butter and jelly sandwich results in eating an enjoyable snack at its completion.
- Teaching a skill in a variety of situations, settings, or with multiple teachers helps promote generalization of a skill. Thus, teaching of toileting skills in a variety of restroom configurations with several different people assisting can increase toileting skills in most community settings.

- Bringing features or common elements of the everyday environment into the teaching situation, helps to generalize skill use in that everyday environment. For example, teaching shoe tying using the individual's shoe and shoelaces instead of common string or pipe cleaners would promote generalization to the real world task.
- Once a behavior has been learned to a consistent high level of performance, one can shift to intermittent rewards so that the skill is more resistant to being extinguished if rewards are not given frequently on some occasions in the future.

Teaching self-management techniques can be useful for promoting generalization. Self-management involves learning to prompt and reward one's own behaviors in various situations outside of direct treatment.

Essential Component 6: Functional Analysis of Behaviors

This section describes issues related to the behavior of individuals with ASD. It includes descriptions of common behavioral issues and causes. Because behaviors are functional for the individual, it is important to understand the intent of the behavior before applying an intervention. This section focuses on understanding behavior and intervention strategies.

It is best used in conjunction with the rest of the document because disruptive behavior has a cause and effect relationship with all other areas of development, inclusion in the community and life experiences. Difficulty communicating needs, a lack of understanding expectations, or a negative reaction to the environment, can contribute to disruptive behavior. Appropriate social behavior is necessary for learning, interacting with peers, and involvement in the community.

In our society, behaviors are often only talked about in a negative context. "His behavior is interfering, disruptive, or self-defeating." It should be noted that persons with ASD may have a dramatically narrower repertoire of behaviors, particularly in social situations. The effort to reduce maladaptive behaviors needs to be offset by equal energy to focus on teaching the individual new, functional, and appropriate behaviors.

Behaviors Serve a Function

Disruptive and disturbing behaviors are sometimes manifested by individuals with ASD. It is important to consider that behaviors can be very functional for the individual yet may result in negative outcomes. Understanding the behaviors of any individual is very complex. Behaviors vary as a result of internal factors (e.g., emotion, puberty, maturation, aging, nutritional changes, overall health, sensory sensitivity) as well as external factors (e.g., changes in environment, social pressures, sleep deprivation, behavior of others, changes in school or personnel).

It is important to identify the antecedents of a behavior and the consequences that reinforce it. This information can be used to change the behavior by altering the antecedents and/or the consequences. This operant conditioning approach is often used in combination with other supports and strategies. To better understand the complexities of behaviors and to identify better interventions, one can also use a systematic procedure called Functional Behavior Analysis (or Assessment), which incorporates the operant conditioning approach.

Functional Analysis of Behavior and Behavior Interventions

The premise of a Functional Behavior Analysis (or Assessment) (FBA) is that all behavior serves a purpose. Behavior often achieves some desired goal or goals. The goal or goals may be escape or avoidance, control (including meeting one's own sensory needs), attention, or getting a specific object, as well as an attempt to communicate.

The goal, therefore, of any behavioral intervention program is to teach adaptive behaviors and to prevent the development of unwanted or inappropriate behaviors. Research has shown this to be an effective strategy in individuals with ASD and other developmental disorders. Functional analysis focuses on the "ABCs" of behaviors (antecedent, behavior, consequence) as a means to understand the purpose or function of the behavior. Such analysis facilitates the development of needed skills and, as more functional and socially appropriate behaviors are learned, problem behaviors are reduced or eliminated. The use of behavioral analysis is a mainstay of successful behavioral intervention strategies for individuals with ASD.

Typically, functional analysis proceeds through the following steps:

- The target behavior (skill to be learned or problem behavior to be eliminated) is defined in terms of observable, measurable behaviors.
- Identify the behavioral antecedents that are needed for the achievement of a new skill or that can trigger or encourage a problem behavior. Common reasons for the failure to attain a learning goal include absence of foundational skills, lack of understanding of the purpose of the activity, internal or external distractions, or inadequate reinforcement strategies. Factors that underlie problem behaviors may include absence of adequate communication skills, environmental events that trigger the behavior, and adult responses that inadvertently encourage the unwanted behavior.

Teachers and caregivers need to view behaviors as communicative rather than an intentional effort to disrupt.

- An intervention to teach a new skill or reduce a problem behavior is developed logically from the information gathered during the functional analysis. The strategy should consider the purpose of the desired skill or the problem behavior, the individual's developmental level, the need for structure and consistency, the intervention setting, and the need for collaboration between parents and professionals in addressing the problem.
- Consequences that strengthen or weaken the occurrence of the target behavior must be identified. Particular attention must be given to individual differences in the effectiveness of reinforcer behavior strategy among individuals as well as the schedule for the occurrence of the consequence.
- The impact of the intervention strategy is evaluated through regular reviews of objective data. Interventions are then adjusted or revised accordingly (see Appendix 6: Functional Behavioral Assessment).

Behaviors Change Over Time

Challenging behaviors that an individual exhibits as a child may disappear with maturity, or behavioral challenges may become more prevalent due to changing conditions. Sometimes the behaviors an individual exhibits do not change but are perceived differently by others as the individual ages and physically matures.

It is important that the behavioral history of the individual be well understood by all persons participating in the care and education of the individual. His or her unique reactions to common as well as novel situations and intervention strategies that have been successful are important considerations in designing successful interventions.

Influences on Behavior

Behaviors are influenced by the characteristics of ASD and by environmental issues. Some behavioral influences include:

Stress/Anxiety

Stress and anxiety are often key factors triggering behaviors characteristic of people with ASD. There are many worries that lead to stress. Such worries may include changes (or anticipated changes) in schedule, interactions with peers, and pressure to perform. Stressors need to be understood, monitored and controlled with care and respect for the individual's perception and future needs. Individuals with ASD may view causes of stress differently and have varied reactions to stress. All caregivers and providers must be aware of and manage their own stress levels. Individuals with ASD experience awareness of and often negative reactions to the stress of others.

Physiological Factors

Challenging behaviors may occur more frequently or intensely when physiological difficulties are present. These factors may include lack of sleep, medication changes, hunger, and illness (chronic or acute). An individual with ASD may not understand why he is experiencing these difficulties and/or may not be able to express these concerns in a functional manner. The functional analysis must assess if these factors are present and their effect on the behavior.

Sensory Sensitivities

Many individuals with ASD present with sensory sensitivities and/or sensory preferences that are very different from the typical population. Behaviors may occur when an individual encounters a sensory experience that is unpleasant or painful. These sensitivities may be auditory, tactile, taste, visual, or others. Additionally, the sensory experiences that trigger a behavior for an individual with ASD may be subtle and generally uneventful for others. At times, simply the anticipation of the experience can trigger a behavioral response. The functional analysis must consider the unique sensory profile of the individual when determining the function of a behavior.

Finally, successful interventions targeting specific challenging behaviors may vary greatly and include a blend of interaction strategies, structure, and medical support. Some problems may need to be tolerated or set aside for a time while focusing on more dangerous or interfering behaviors (i.e., pick your battles). Successful interventions sometimes require an adjustment period, during which the individual's behavior may seem more challenging than it was prior to intervention. Seek agreement and commitment from all team members and allow interventions to work by implementing them consistently and giving them time.

Positive Behavior Support

Positive Behavior Supports (PBS) work hand in hand with the Functional Behavior Analysis process described above. PBS is an approach or process that can be utilized to develop individualized interventions for children presenting with more complex or severe behaviors. The strategies used within a PBS plan to bring about positive behavioral changes in children, include the teaching of new skills, preventing the occurrence of the challenging behavior, and supporting the child in achieving meaningful, long-term outcomes. This is a much more proactive approach to dealing with difficult behaviors in that it is a proactive versus a reactive strategy and is also focused on long-term interventions as opposed to a quick fix.

The PBS process begins with the formation of a team of individuals who have concerns about a child's behavior. PBS is most effective when it is implemented across all environments – consistency and continuity are key. The next step in the process is to conduct a FBA. After the function of the behavior

is identified the team can begin formulating the behavior support plan (see Appendix 6: Functional Behavioral Assessment).

It is within this plan that:

1. Specific strategies for modifying the curriculum, environment or activity are identified,
2. Specific procedures for teaching the new skills are identified, and
3. Strategies are implemented to ensure that the new skills are learned and that the challenging behavior is not maintained. Each of these steps will be further explained in the following paragraphs.

Frequently, modifications can be made to the environment, curriculum, delivery of instructions etc. to reduce the likelihood that the child will need to rely on the challenging behavior for whatever function it serves. Some strategies and modifications to consider are reviewing rules, allowing for the child to make choices, reducing distractions, using visual supports such as visual schedules and instructions, using timers to help facilitate transitions, and providing the child with verbal and visual strategies to assist with self-regulation strategies.

The second step in the PBS process is the actual teaching of replacement skills that serve the same function as the challenging behavior but are more appropriate and desirable. It is critical the replacement skills be efficient and effective. They need to work as well or better then the current undesired behavior that they are engaging in. It is also important to consider the child's current skill level including cognitive level and communicative abilities when determining replacement behaviors. Ensure that the replacement skill being introduced addresses the function of the challenging behavior. For example, if the child wants out of an activity then teach the child to communicate the concept of finished or break.

The final step in the PBS process is to ensure that the challenging behavior is not maintained and that the new skills are learned and applied. It is vital that all adults interacting with the child respond in a consistent manner that will make the challenging behavior ineffective. In addition, rewards for appropriate behavior need to be equal to or exceed the rewards the child gives themselves through the use of the challenging behavior. A good rule of thumb is that the appropriate behavior needs to be positively reinforced four times for every one display of the challenging behavior. Data needs to be gathered on the frequency of occurrence of the challenging behavior and the effectiveness of the replacement behavior to determine the success of the PBS plan.

A majority of the information in the above PBS section was adapted from the Center of Social and Emotional Foundations for Early Learning. Their web site contains many help sheets and training modules on behavior, FBAs and PBS plans. For additional support and information on this subject, go to **www.vanderbilt.edu/csefel/contact.html**.

Behaviors Require Brainstorming and Teamwork

Successful intervention for challenging behaviors requires all persons involved with the individual (the team) to work together to meet the needs of the individual with ASD. Flexibility is required on the part of all team members to establish and maintain communication with each other and to apply consistency in implementing the agreed upon intervention(s).

The team must assess the situation, identify the individual's needs and abilities and implement strategies to assist the individual in learning and using appropriate behaviors. The process of assessing, teaching and learning appropriate behaviors may sometimes proceed quickly or may require a long period of time, the

involvement of many people to assist, and the systematic testing of a variety of strategies.

There is a dynamic relationship between the educator, parent, others involved and the person with ASD. Priorities and goals of each are contributors to problems (lack of unity and confusion) and successes (cooperation, compromise, and consistency). Individuals working together as a team must be willing to share resources and personal limitations. They must be willing to compromise. They must be willing to make the most of the creativity that can exist within the team. Be prepared to do things differently.

Essential Component 7: Communication

The Communication section describes the unique patterns of communication associated with individuals with ASD. Included are ideas on how to assess the purpose of communication and strategies for improving communication. This section is best used in conjunction with the rest of the document because the ability to communicate affects all other areas of learning, socialization, and behavior, and they in turn are affected by communication abilities.

Supporting all forms of communication—verbal, signing, pictorial, augmentative devices—(and often a combination of more than one) promote learning.

The ability to communicate one's feelings and thoughts to others has a profound effect on quality of life both immediately and long term. Without an effective communication system, it is very difficult to navigate through life. In addition to individuals who have obvious communication challenges, there are many individuals with ASD who may only appear to be capable communicators. In fact, those individuals may not be effective communicators and that can limit their ability to meet their potential.

Communication difficulties in both verbal and nonverbal are inherent to the diagnosis of ASD. The normal developmental sequence of communication is disrupted in persons with ASD. Communication skills can range from nonverbal, gestural, the use of single words to verbal conversation and may include the following communication difficulties:

- Perseveration (repetitive verbal and physical behaviors),
- Echolalia (immediate and/or delayed "echoing" of words, music, phrases or sentences),
- Hyperlexia (precocious knowledge of letters/words or a highly developed ability to recognize words without full comprehension) and to a lesser degree,
- Dactolalia (repetition of signs), pronoun reversals, inappropriate responses to yes/no questions, and difficulty responding to "WH" questions.

Communication difficulties impact all other areas of learning, socialization, and behavior. When designing appropriate intervention strategies, it is important to understand the individual's receptive (comprehension) and expressive communication skills. Stressful situations that increase anxiety often interfere with the individual's ability to communicate. Difficulty understanding humor, idioms ("keep your eye on the paper"), sarcasm and other complex forms of verbal and written expression is common.

Even the highly verbal individual may understand and use literal (concrete) language but have difficulty with abstract concepts. A person's communication ability usually changes over time; therefore, it is important to maintain an ongoing communication assessment from diagnosis through adulthood as this provides current information, which is necessary to support appropriate communication strategies.

It is important to understand the individual's unique communication style and/or skills which leads to

development of a method for communication. Supporting all forms of communication - verbal, signing, pictorial, augmentative devices (and often a combination of more than one) promote learning.

In addition to the development of an effective communication system, consider use of the following modifications and strategies.

Modifications

- The communicating partner needs to fully understand that situations, certain individuals, sensory issues and stress will affect the quality of communication and the communication intention.
- Modify the speaker's language and provide visual supports if there is no response or undesired response to a direction or question.
- Allow time for auditory processing and formulation of information. For example, instruction and conversation may need to move at a slower rate.
- Develop a protocol to gain the individual's attention. The protocol should include how to initiate joint focused attention.

Strategies

- Encourage meaningful imitation. Since imitation is one of the precursors to the development of functional language, build in ample opportunities for activities to develop imitative skills.
- Help the individual focus attention on the speaker. This will maximize the impact of any direction, question, or information.
- Determine the communicative intent and other possible functions of non-verbal and verbal behaviors to establish their meaning. For example, if a person hits when frustrated, teach an appropriate behavior that communicates that they are frustrated, reduce the frustration or both.
- Integrate communication strategies into all daily activities. Teaching communication strategies in a step-by-step approach, starting in an organized environment, will assist generalization to other environments.
- Use vocabulary and grammatical structure at the individual's comprehension level.
- Consider using rhythm and music.
- Teach turn-taking and joint attention.
- Provide the individual with multiple opportunities to initiate interactions, make choices, and have peer-to-peer contact on a daily basis across all environments.
- Consider supporting receptive communication as well as expressive communication through both nonverbal and verbal methods: visual supports (object boards, pictures, gestures, sign language) and voice output communication devices.
- Facilitate the initiation of conversation and provide opportunities to practice language rather than waiting for the individual to initiate contact.
- During transitions from classes, buildings, work: offer a summary of successful communication strategies to appropriate personnel.

Essential Component 8: Assistive Technology

Assistive technologies are applications (either hardware or software) designed specifically to assist individuals with disabilities to overcome barriers. In compliance with IDEA, schools are responsible for

determining what assistive technology(ies) is/are appropriate for an individual with a disability in order that the individual may receive a free and appropriate public education in the least restrictive environment.

Assistive technology is defined as…"any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities" (IDEA, 2004). In addition, assistive technology services must be provided in order that the individual with a disability is able to successfully select, acquire, and use an assistive technology device.

Caution should be taken not to limit the consideration of assistive technology to expressive communication only. While augmentative communication devices can support a significant "breakthrough" for some individuals with ASD, there are many other ways in which to use technology within an educational program for individuals with ASD. These are categorized in several categories. (see Appendix 14 section on Assistive Technology.) Examples follow.

"No" Tech Tools

- No tangible item or material is involved
- Clear physical and visual boundaries
- Elimination of extraneous visual stimulation
- Proximity of staff to individual

Low Tech Supports

These require the individual or staff person to utilize an item that typically is not electronic or battery operated. These items are typically low-cost and easy to use.

- Dry Erase Boards
- Clipboards
- Three-ring binders
- Picture Symbol Cards
- Choice Board (no voice output)
- Ear Plugs
- Use of a pointer
- Visual Schedules and Routines

Mid-Tech Tools

These include battery-operated devices or simple electronic devices requiring limited advancements in technology.

- Tape recorder
- Timers
- Calculator
- Head Phones
- Assistive Listening Devices
- Portable Word Processor

- Simple Voice Output Devices

High Tech Tools

These complex, typically high cost devices require some training for effective use.

- Computer Software and Adaptive Computer Hardware
- Video Cameras
- Complex Voice Output devices
- PDA, I-Pod

Educational teams should consider carefully the advantage of assistive technology in all aspects of the individual's program. Inclusion of "low tech," as well as "high tech" tools should be considered. Finally, teams should identify how technology may assist the individual not only to effectively communicate, but also to access the general curriculum and to make progress on individual goals and objectives.

Essential Component 9: Sensory Motor Processing

This section describes issues in sensory motor processing for individuals with ASD. It includes a definition and explanation of terminology in order to provide a common understanding of the issues involved. It also includes practical strategies and guidelines for developing sensory supports in all environments. This section is best used in conjunction with the rest of the document because the individual's ability to process sensory input from the environment affects all other areas of learning, socialization, and behavior.

Sensory motor processing challenges limit the experiences and environments in which an individual with ASD can function successfully. The identification of strategies to address these challenges can expand the opportunities for relationships, work, and leisure in which individuals with ASD can participate.

Sensory motor processing involves the ability to take in information from the environment, organize it, make sense of it, and formulate a response. Normally, this happens automatically. When the system is working well, we can screen out unimportant stimuli, pay attention, respond appropriately and move through the environment fluidly. When the sensory system is not functioning well, (regardless of the reason), an individual may find it difficult to pay attention and formulate responses that make sense. In addition, people may shut down or overreact to incoming stimuli and have difficulty moving safely and freely.

The senses that the brain uses to take in information include the well-known senses of sight, hearing, taste, and smell, and three other systems that are very powerful - the tactile, proprioceptive and vestibular systems. The tactile system involves information that comes from contact with the skin. Light touch can activate the fight-flight-fright response and deep pressure touch can calm the nervous system. The proprioceptive system registers where your body is in space through the joints, muscles and tendons. The vestibular system assists in balance, coordination and movement.

It is important to be aware that individuals with ASD will likely have difficulty in one or more of these sensory systems. For example, over-sensitivity to sounds, light, touch, or movement can indicate sensory defensiveness. This may be characterized by unexplained emotional outbursts, stereotypic behaviors such as rocking and pacing or fearful avoidance of contact with people and objects in the environment.

Recommended strategies for working with individuals who demonstrate defensiveness include:

- Avoid touching the individual without giving a verbal cue first.
- Make boundaries around the individual's workspace and establish each individual's space as part of the classroom rules, using carpet squares, masking tape or furniture.

- If the individual needs to be touched, use a firm but kind touch, rather than a light tap.
- Decrease the amount of visual and auditory distractions in the room.
- Provide structure and predictability.
- Provide additional support during transitions between lessons and between places in the building.

Other sensory challenges may result in problems filtering incoming stimuli, organizing the information and developing a response to it. This may be characterized by difficulty directing and shifting attention, maintaining alertness for a task and executing a sequence of steps to complete a task. Specific strategies must be tailored to the individual's needs and challenges.

The following suggestions serve as guidelines when developing sensory supports in all environments:

- Determine an individual's tolerance or comfort with input from various sensory channels.
- Identify behavioral indicators of excessive stimulation (e.g., covering ears or eyes with hands, body rocking, hand flapping, withdrawing).
- Conduct an environmental assessment to identify problem stimuli (e.g., lighting, noise, odors, textures, and limitation of personal space).
- Proactively modify the environment to accommodate sensory motor processing needs (e.g., reduce noise with sound absorbing materials, keep visual stimuli to a minimum, create study carrels and clear boundaries for work areas).
- Determine the need for appropriate sensory input throughout the day (e.g., deep pressure, movement, and materials to manipulate during instruction or work time).
- Provide opportunities for heavy work (e.g., activities requiring exertion) throughout the day. Examples include stacking/un-stacking, pushing carts/trash cans, holding doors, washing chalkboards, crushing aluminum cans for recycling, and sweeping floors.
- Provide access to suspended equipment (e.g., swing in corner of classroom or gym) if indicated.
- Incorporate movement activities and manipulative materials into instructional time and provide breaks for additional physical activities and/or sensory input as needed (e.g., exercises, walks, mini-trampoline).
- Schedule regular "sensory breaks" during the day as needed. Activities during these times may include joint compression/traction, using hand held objects that provide vibratory or pressure touch input, movement, or calming music.
- Provide opportunities for the individual to indicate a need for strong sensations or access to equipment at times other than what is regularly scheduled as part of the routine.
- Determine environmental/task modifications that may help in reducing the motor challenges facing the individual (e.g., desk/chair height, writing utensils, position/type of work materials).
- Allow the individual to stand at the chalkboard or an easel to work. Standing will provide needed input into trunk musculature that will help the individual stay alert and focused on the task.

Essential Component 10: Social, Emotional, and Sensory Regulation

Social, emotional, and sensory regulations (modulation) are skills difficult for individuals with ASD. These skills lie at the core of an ASD, making interpersonal interactions overwhelming, frustrating, and stressful.

Often, these difficulties portray the person with autism as "choosing" to be disengaged from social interactions due to a lack of interest or desire, even when that is not the case. Communication difficulties combined with atypical visual and auditory perception in ASD makes traditional learning challenging. Strategies such as those of the *Incredible Five Point Scale* (Dunn Buron & Curtis, 2003) and *How Does Your Engine Run?® A Leaders Guide to the Alert Program® for Self-Regulation* (Williams & Shellenberger, 1996), help persons with autism learn; social, emotional and sensory regulation skills.

How Does Your Engine Run helps address the parent and professional concern of what to do and more importantly increases the person with ASD understanding of how they can manage themselves, and come to know what to do, and when to do it.

The 5-point scale is a technique used to help a child break down an abstract concept into a visual system that is easier to understand. For example, a concept such as using appropriate voice volume can be broken down into a 5-point scale, with 1=no voice, 2=whisper, 3=normal voice/dinner time, 4=loud voice/ playing outside, and 5=screaming. A visual representation of the scale is used as the scale is introduced and explained to the child. It is reviewed repeatedly so it becomes very familiar.

A picture of the scale is later used as a visual support to remind the child to use an appropriate voice level. The teacher points first to the level the student is using, and then slides her finger down to the appropriate level for a given situation. For example, if the child was screaming while the family was in the store, the parent would point to number 5, then move her finger down to 3 – an acceptable level.

A professional who is knowledgeable about sensory motor processing should be consulted for specific strategies for any individual. Generally, this professional is an Occupational Therapist.

Essential Component 11: Social Development

Impaired social development is one of the three core challenges in individuals with ASD. Social development is dependent on other areas of development, especially communication and sensory motor processing. Socialization requires communication skills in order to have successful social interactions and group experiences. In addition, the ability to seek out and enjoy the social interaction is dependent on the individual's ability to focus on the interaction rather than coping with the environment. Being capable in social situations allows the individual to successfully engage in activities such as holding a job, maintaining a living situation and taking care of basic needs while improving the quality of life.

The social challenges in ASD are influenced by the individual's age and severity of impairment. Usually the challenges are most severe in the young child with variable improvement over time that, in part, is influenced by cognitive potential, underlying etiology, if known, and comorbid conditions. The lack of social understanding affects all social aspects of work, school, interpersonal relationships, recreation and community involvement that all play a part in the building of self-esteem.

Social skills may not generalize without specific training; therefore, it is important that social competence be reinforced in all environments (including the workplace), especially for those individuals who are in transition.

Specific strategies and supports for social development and related skills must be provided to individuals with ASD.

Social skills may not generalize without specific training; therefore, it is important that social competence be reinforced in all environments (including the workplace), especially for those individuals who are in transition. Specific strategies and supports for social development and related skills must be provided to individuals with ASD.

There are several levels to consider when providing social strategies and supports. When assessing the

social competence for individuals with ASD, it is important to look at the quality (content and meaning) of the social interactions vs. the quantity (amount) of social interactions. One individual may have difficulty tolerating others in their personal space while others may "get in your face" and talk incessantly on one or two self-interest topics. Supports need to be developed based on the strengths and interest of the individual. That is, one individual may need to learn social skills to initiate social communication in a one-on-one setting with introduction to social situations in small steps; whereas, an individual with Asperger Syndrome may need to have a repertoire of social topics to learn how to reciprocate and maintain social communication.

Assessment of social competence should include considerations, for example:

- Age of individual
- Sensory motor processing challenges
- Imitation skills
- Receptive and expressive language skills
- Cognitive abilities
- Individual's interests and skills
- Environment where socialization occurs

When developing social goals, the following areas need to be addressed:

- Imitation and joint attention (attending with others)
- Understanding personal space
- Asking for help and assistance
- Acceptable environmental behaviors, such as not picking nose in public, bathroom etiquette, etc.
- Emotions of self and others
- Identification of emotions and where they occur
- How individual actions affect others
- Initiating, maintaining and reciprocating social interactions
- Listening and attention skills
- Ability to abstract and infer language
- Understanding perspective taking
- Getting the Big Picture
- Humor, slang, sarcasm, joking, teasing
- Accepting rejection by peers
- Playing games, winning and losing graciously
- Turn-taking, waiting for turn
- Understanding non-verbal communication (includes body language, facial expression, proximity or personal space, gestures and eye contact).
- Age appropriate behavior with the opposite sex, e.g., recognizing unwanted sexual advances and dealing with them appropriately, understanding appropriate sexual expression and seeking privacy for any sexual expression, finding appropriate ways of seeking and giving affection.

- Typical peers' understanding and successful ways to interact and support the individual with ASD.
- Appropriate workplace behavior as a part of the transition from school to work. This includes the use of vocational language, how to take work breaks, dealing with the public, and working with superiors, subordinates and work peers. In many cases, the degree to which a person with ASD "fits in" with, and is accepted by, their work peers will determine their long-term job success. The employer may require assistance with appropriately introducing the person with ASD to the workplace and educating the workers with how to have a meaningful work relation with that person. On the other hand, once acceptance is gained from work peers, the person with ASD often has a very strong, vocal support network that greatly enhances the probability of their long-term job retention and success.

A number of strategies and supports are available to teach appropriate socialization and social understanding. Based on the assessment of social abilities, teaching of these social skills may occur in one-on-one, small group, large group or a combination of these teaching environments. Due to generalization issues, a plan should be developed and supported to expand socialization and social understanding into multiple environments.

Several broad categories of strategies and supports to consider include:

- Rehearsal – Scripting, Modeling and Practice
- Role Play
- Social Curriculums
- Social Skills Manuals
- Visual Supports
- Peer Models
- Structured Peer Supports
- Social Narratives
- Video modeling

Regardless of the environment used or the strategies selected, instruction in socialization and social understanding must be provided in a well-planned and systematic manner.

Essential Component 12: Inclusion with Typically Developing Peers

Models of language and social interactions are an important component of a successful program for individuals with ASD; however, the mere presence of typical peers does not constitute successful social-communicative interactions. Coordinated efforts across school, home, and community environments can assist to promote natural peer interactions. Families and professionals may focus on the implementation of a variety of strategies in these environments, including activities, routines, and situations to promote peer-peer interactions.

When selecting strategies and coordinating a plan to support the individual with ASD in inclusive activities, the IEP team should consider the following guidelines:

- Assess the person's individual need for inclusion with typical peers. Provide a natural progression of inclusion (e.g., individual to segregated classroom to small group to large group instruction).
- Plan and schedule activities that promote inclusion and prevent segregated grouping.
- Continue to emphasize the acquisition of skills that will allow the individual to benefit from inclusive experiences.

- Include in the transition plan the commitment of all team members, assessment of placement options (evaluation of a individual's learning style and teachers' instructional style), skills the individual needs for integration, and training for instructor and support staff.
- Provide specific guidance to peers to recognize and respond to verbal and nonverbal communicative behaviors of the individual with ASD. Include strategies that focus on the peer's ability to initiate, respond to, and maintain social-communicative interactions with the individual.
- Incorporate environmental supports (such as charts, cue cards, directions) in conjunction with peer models or as alternatives to direct adult support.
- Assessment of the amount of time the individual can be successful in an inclusive setting.

Essential Component 13: Progress Monitoring

Assessment is vitally important to determine the effectiveness of any intervention. The Individualized Family Service Plan (Birth through Two program, DSHS) or Instructional Education Program team (Three-21, OSPI) must determine how often the data will be collected, recorded and the criterion for determining when a particular intervention is successful or unsuccessful. In order to make collecting data easier, the University of Washington's Experimental Education Unit has developed *Show Me the DATA!* a workbook of forms and a CD which is available for purchase at **http://depts.washington.edu/dataproj/**.

Essential Component 14: Supported Transitions Across Multiple Environments

Transition Overview

Individuals with ASD typically have difficulty handling even minor transitions and environmental changes in their day-to-day life. These can cause significant behavioral outbursts and regression in learning if they are not negotiated in a planned manner. Transition to a new service system leads to many changes for the individual and family including changes in service providers, location and, in most cases, service procedures.

Considering the potential impact of these changes on the individual, family, providers, and educators, certain steps need to separate to make the transition as smooth and problem free as possible.

The following provides guidance for accomplishing successful transition.

- Awareness of the problem and appropriate planning are key to making successful transitions for individuals with ASD. It is important to know when an individual with autism has particular difficulties with transitions and under what circumstances these occur. Some individuals will have difficulty with transitions that involve changing physical locations, some have difficulty with changes in activities, and others have difficulty with transitions among adults or people with whom they are unfamiliar. Once the circumstance is understood, the plan for supportive, preventive measures can be put in place.
- Individuals with ASD should be informed several times about upcoming changes several times before transitions are made. Explain "when" and "what" the transition will be in terms they understand. Major changes in daily schedules should be announced the day before, the morning of and just before the actual change. Providing a "transitional" object or picture may help some individuals. This is usually done with a small object or picture uniquely associated with the next activity or physical location where the individual is transitioning.

For example, a ball typically used at recess, given to the individual upon leaving the classroom may ease the transition to the playground.

- Some individuals have difficulty transitioning from a preferred activity to a less preferred activity. Transition to the less preferred activity may be facilitated by indicating to the individual that he will have an opportunity to return to the preferred activity. Depending on the individual, return to the preferred activity may need to take place immediately or may be delayed until a later time. In addition, clearly explain the expected transition to the individual.

  This may be done verbally, using pictures, written words, or schedules to indicate the activities and in what order the individual will be expected to participate. As activities are completed, the individual removes them from the schedule list. This not only adds predictability to the individual's life, but also begins building steps towards early self-management skills.

- Major transitions such as entering a new classroom with a new teacher present transitional issues for everyone involved. The teacher should attempt to know as much as possible about the individual before the transition. This is particularly important for individuals with ASD, because many teachers have limited experience with these individuals, and individuals with ASD vary widely in their educational needs. The family and the individual may also need increased supports for making this a successful transition. Complete planning and obtain resources before the transition occurs. It may be helpful to have the individual and parent visit the new classroom and teacher before classes begin.

  Planning, which begins by the sixteenth birthday or earlier, is the key to a positive outcome and obtaining a job.

  Parents should be given as much information about the new setting and its activities so that they may feel comfortable and prepare the individual more fully for the new expectations. Some individuals may need increased staffing support for a brief period at the beginning to provide instructional, prompting, and behavioral management assistance. It is important to provide such supports in a preventative and proactive manner instead of waiting until the individual has difficulty and thus develops an aversion to the new environment.

- The transition from school to work is often considered the most significant transition that an individual will face during the school years. Proactive planning, which begins by the fourteenth birthday or earlier, is the key to a positive outcome and obtaining a job. Situational assessments and vocational experiences in real settings are key to enhancing this probability. The training of parents, administrators, school staff, and others to assist in this transition is critical. Full participation of the individual who is transitioning from school to work also promotes a successful outcome and minimizes anxiety.

Essential Component 15: Sexuality

"*It is a paradox that the individuals about whom we have the most ambivalence regarding sex education are the persons who most need it*" (Sgroi, pg. 204). "*I believe that sexuality education begins at birth*" (Monat- Haller, pg. 41).

This section describes issues relating to the sexual development of individuals with ASD. It includes an understanding of all of the areas that are affected by a person's developing sexuality. This section is best used in conjunction with the rest of the document, because sexuality is associated with the ability to communicate, to process sensory stimulation and to behave appropriately in private and social situations.

Sexuality is a natural part of life that everyone has the right to express in appropriate ways. A healthy sexual life contributes to personal dignity, interpersonal relationships and a full participation in life. Many individuals with ASD have social, communication and sensory difficulties that can impede the development of a healthy sexuality; therefore, it is important not to overlook this area of development.

Characteristic behaviors and communication barriers displayed by individuals with ASD pose many challenges in the classroom, the community and at home. These same challenges may cause difficulty for the individual with ASD in the expression of sexuality. Often the individual's behavior is misunderstood by others.

Knowledge of the characteristics of ASD will enable caregivers to better understand these behaviors as they relate to sexuality, as well as to maintain a positive approach to learning and living; therefore, comprehensive educational programs for individuals with ASD must address the issues of sexuality.

An ongoing hierarchy of skills training should be included in any educational program for individuals with ASD. This training may begin in the early childhood years with developing an understanding of one's body, how it works, and how it changes. As the individual develops, educational programs should teach skills for appropriate social interactions, as well as assist the individual to understand that successful relationships must be mutually fulfilling.

Individuals with ASD need to:

- Have the opportunity to make friends.
- Learn skills that will assist in making friends.
- Care for their personal health and hygiene.
- Understand how to interpret changes in their bodies as they develop.
- Learn the social consequences of inappropriate behaviors.
- Have outlets for their sexuality.
- Have help in understanding these needs and in understanding the needs of others.

All parties associated with the effective social-sexual development of persons with ASD must resolve all concerns and communication challenges associated with sexual subject matters. There is much we do not know about the feelings, desires and drives of individuals with ASD. It is clear, however, that many persons with ASD have a sex drive and most often express it through solo masturbation rather than through sexual experimentation with others. Families need to recognize the importance of this in order to remove the taboo atmosphere that surrounds masturbation behaviors. There is a time and a place and there needs to be some reasonable dignity and privacy associated with it.

Common Concerns Regarding Sexuality and ASD

a. Public or inappropriate displays of sexual behaviors (exposing self, public masturbation, etc.)

b. Self-injurious masturbation

c. Social contact or touching problems

d. Problems with privacy issues

e. Inability to empathize with others

f. Inability to distinguish exploitative behaviors either towards others or by others

Sexuality Teaching Techniques

It is necessary that teaching techniques regarding sexuality be holistic, functional and concrete. Efforts to address sexuality will include a broad range of issues and objectives.

A holistic approach will consider all aspects of social preparedness for relationships. It includes:

- An understanding of one's own body, its function and its appropriate care.
- The development and use of concrete language for body parts and functions.
- Special scripts and rules to aid in the understanding of the feelings and needs of others.
- Similar scripts and rules for the appropriate time and place for behaviors of sexual expression.

Once the individual with ASD develops social understanding and awareness, generalizing the information from one situation to the next can be difficult, especially if the rules are unclear; therefore, it is best to develop rules for appropriate behavior that are functional. Many times, rules are stated as expectations with defined consequences. Most people attempt to follow these rules, as they help in successful relationships and in life. As required, individuals will also modify rules and behavior to fit the situation.

For example, people generally use eye contact with others as a way to indicate interest and respect. In certain situations, such as in elevators, this rule changes; in elevators, eye contact is not welcomed and can be considered threatening. Individuals with ASD will have difficulty predicting these type of expectations unless they are specifically taught about, and supported in, these confusing situations.

Temple Grandin (1995) organized situations by categorizing them into three categories: really bad (stealing, property destruction and hurting others), sins of the system (smoking, public sexuality, cursing, etc.) and illegal but not bad (speeding, double parking, or jay walking). Temple described that she does not have any social intuition and she relies on pure logic. She categorizes rules according to their logical importance and not by her emotion. Her insight is helpful in understanding that persons with ASD may not draw from common sense but from rote memory of their repertoire of social rules.

Concrete lessons delivered in a very structured way provide the best vehicle for learning for those with ASD. *Social Stories*, the work of Carol Gray, provides a non-threatening vehicle for rehearsal of appropriate behaviors. Rules scripts as described by Mirenda and Erickson (2000) provide similar channels for facilitating social cues that aid the individual in novel situations. Using strategies, such as those described above, enables the teacher to give thought to specific terminology and its potential for confusion. Specifically, discussions of a personal or sexual nature are often rich with confusing messages. For example, using the phrase, "the barn door is open" as a reminder that an individual's zipper is down could turn out to be a confusing and unsuccessful interaction for an individual with ASD.

Essential Component 16: Lifelong Support

The mandated educational services for individuals with disabilities including ASD end at age 22; however, there is a continued need for support for these individuals throughout their lifetime. These needs are highly individualized and are influenced by changes in environment, health, social, and employment situations. Continued supports will assist in maintaining stability for the person with ASD and facilitate successful inclusion in the community.

Using self-determination as the guiding principle, services and supports should be delivered according to indicated interest and choices of the individual (see Appendix 5: Inclusion).

Supports may be needed in the areas of:

- Employment
- Education
- Independent Living
- Community Living: Residential
- Extracurricular Activities
- Community Participation
- Health services and professionals
- Communication
- Social relationships (at all levels of intimacy)
- Finances

Chapter 7: Community Transition

This chapter builds upon the previous chapters by focusing on preparation for and transition to life beyond high school. In this transition, individuals with Autism Spectrum Disorder (ASD) leave an entitlement system and enter systems based instead on eligibility and availability. In order to take full advantage of the options available at transition, individuals must be equipped with the necessary skills to live, work, and play in the community. Each individual must be properly prepared to be a contributing citizen.

Although this section covers topics related to children's lives beyond high school, it urges parents to work on them even while their children are still in school. This chapter includes many suggestions for planning for children's transitions from a school program to adult services, employment, and living in the community. It also introduces important legal and financial planning issues that every family should think about.

It is important that parents not wait until the child is a teenager to formulate plans for the future.

One of the most challenging times for families and individuals with ASD is when an adolescent is about to transition from a school program to the uncertainty of adult services. Questions about postsecondary education, vocational training, employment, community living, and sources of financial support for the individual with ASD must be addressed. The Individuals with Disabilities Education Act (IDEA, 2004) requires that transition planning for this shift to adulthood and adult service systems begin by age 16 years, although it may begin earlier if the Individualized Education Program (IEP) team agrees.

Basic Principles of Transition:

1) **Start early.**
2) **Involve all service agencies and funding sources.**
3) **Secure a job before graduation that can be retained or identify post-secondary education options.**
4) **Knowledge planning with family involvement.**

The student, parents, and members of the IEP team should work together to help the student make choices about the individuals' path for the future. This will involve discussions about where to live, what kind of work to do, and what recreation and leisure time activities the person would like to be involved in when not working. Transition planning through the IEP process identifies the student's goals and a plan for reaching them in each of these areas.

One of the biggest changes that parents face at the time of a child's transition from education to community services is the shift from the mandated services of education to the eligibility-driven services of the adult service system. All children are entitled to educational services. But in the adult service system there are no entitlements. Individuals must "qualify" or be determined eligible for services. Transition services within education should support parents and the child in applying for the services for which they are eligible.

In addition to the transition planning, IDEA requires that the school provide the student who is transitioning out of high school a summary of his or her academic achievement and functional performance. The summary is to include recommendations as to what assistance is necessary for the student in order to allow her or him to meet the postsecondary goals.

The section on Community Transition is best used in conjunction with the rest of this document as transition activities will require many of the same types of strategies and supports identified for individuals in the early years of education. Some of the necessary skills an individual needs to transition to adult life include a communications system, the ability to integrate/self modulate sensory input, and socially appropriate behavior. The extent to which an individual is able to transition from individually focused activities to an adult life, particularly employment, determines the quality of life after school.

The stakes are very high. During the school years, parents and educators must partner and strive to prepare individuals with ASD for 40-60 years of life in the community. The focus of this section is to enhance the information in previous chapters in order that the dreams and personal visions of people with ASD become a reality.

School to Adulthood

Overview

Transitioning from school to adulthood is a process of preparing a person with ASD to be part of the community. In order to accomplish this, individuals and family members must have a vision of what this life after school will resemble. This vision will drive the transition services in school and beyond. To make the vision a reality, the individual's family members and other members of the transition team must be committed to the process. Depending on the severity of the disability of the individual with ASD, this transitioning process may take a long period of time, with the possibility that the individual may require and need to receive long term supports.

Components to Achieve

- Develop vision statements of expected outcomes with the full input from the person with disabilities to the greatest degree possible at every stage to determine if the path being followed is leading to the work outcome they desire.
- Determine the dreams, interests, strengths, skills and barriers for the individual who will make the journey.
- Include pragmatic, person-centered, and individualized strategies which focus specifically on the vision. These strategies should support outcomes which will occur in the community.
- Develop collaborative efforts among student, family, school and external agencies. Design a course of action that identifies how the receiving agency will assume the supports and responsibilities of the process.
- Identify the person within schools and agencies who will accept individual responsibilities in the support and "hand off" the process.
- Assess progress at each stage. Reset tactics, funding, and supports when necessary.
- Take supported opportunities to facilitate independence. Learn from mistakes and incorporate lessons.
- Take advantage of new opportunities made possible by changing "best practice" laws and funding.
- Capture, retain and utilize the necessary financial support at each stage of the temporal passage.

- Have a long term and ongoing training program for parents, guardians, educators, administrators, and adult service provider agencies regarding the transition process, people or agencies involved, financing systems, etc. This should include the benefits of community employment vs. sheltered employment and post secondary education options.

The National Information Center for Children and Youth with Disabilities (NICHCY) has published a Transition Summary series to help families and students with disabilities focus on taking definite steps toward a successful transition. Below is an adapted portion of NICHCY Transition Summary, (No. 7, September 1991), available in its entirety from **www.nichcy.org/educatechildren/transition_adulthood/pages/transition101.aspx**.

Middle School: Start Transition Planning

- Involve the child in career exploration activities.
- Visit with a school counselor to talk about interests and capabilities.
- Have the child participate in vocational assessment activities.
- Along with the student, use information about interests and capabilities to make preliminary decisions about possible careers (academic versus vocational or a combination).
- Involving the student, make use of books, career fairs, and people in the community to find out more about careers of interest.

Keep in mind that while self-determination needs to be considered, students with ASD may mature more slowly than others. Therefore, their timetables for independence may be longer. **Beware of eliminating options too early based on academic and behavioral expectations they may not have achieved at the same age as their peers.**

High School: Define Career and Vocational Goals

- Develop a transition plan that will drive the IEP. Work with school staff and community agencies to define and refine the transition plan.
- Help identify and ensure that the student takes high school courses that are required for entry into college, trade schools, or careers of interest.
- Help identify and make sure the individual takes vocational programs offered in high school, if a vocational career is of interest.
- Encourage the student to become involved in early work experiences, such as job try-outs, summer jobs, volunteering, or part-time work.
- Reassess interests and capabilities, based on real-world or school experiences. (Is the career field still of interest? If not, redefine goals.)
- Make sure the student participates in ongoing vocational assessment and identify gaps of knowledge or skills that need to be addressed and address these gaps.

Elements Not to be Overlooked

- If eligible for vocational rehabilitative services, make sure the individual works with a vocational rehabilitative counselor to identify and pursue additional training or to secure employment (including supported employment) in his or her field of interest.

- If the individual is not already receiving Supplemental Security Income (SSI), contact the local SSI office shortly before he or she turns 18 years. Family income is no longer considered in determining eligibility for benefits after the person's 18th birthday. If eligible for SSI benefits such as SSI income, find out how work incentives apply.

- Help identify and confirm that the individual takes any special tests necessary for entry to post-secondary schools (e.g., PSAT, SAT, ACT). Deadlines to apply for this testing are generally earlier when accommodations are requested.

- Visit the institution, contact the office of disability services at the institution, and confirm that the accommodations needed for college coursework are available.

- Contact the Division of Mental Health at DSHS for Regional Support Network (RSN) information in Washington counties regarding mental health assistance to determine a child's eligibility for services, including Medicaid and waiver services. Even if the individual can be maintained on a parent's medical insurance plan, Medicaid can be useful as supplemental insurance. In addition, Medicaid eligibility is required for many adult mental health services.

- Contact agencies that can help, such as disability-specific organizations like the state or local chapter of the Autism Society of America. Ask about all services for which the student might be eligible.

- Continue to work through the plan by following through on decisions to attend postsecondary institutions or obtain employment.

Education and Training Prior to Employment

- Have the IEP team and other disability support organization(s) help identify postsecondary institutions (community colleges, universities, vocational programs in the community, trade schools, etc.) that offer training in a career of interest for the individual.

- Identify the accommodations that would be helpful to support the individual. Make sure that documentation is current on the student's IEP. This will support any request for accommodations at an educational institution. Find out if the educational institution makes, or can make, these accommodations.

- Write or call for catalogues, financial aid information, and request an application from appropriate community colleges, universities, or trade schools.

Practical Tips for Transitions to Work after High School

Getting Prepared

- Behavior needs to be understood, managed, supported, and appropriate for the expected outcomes.

- The individual needs a communication system that allows the individual to engage in functional and reciprocal communication with people in his or her environment.

- The IEP should emphasize development of vocational independent living and community participation skills and supports.

- Access various agencies that will be needed for support during school and after graduation (as soon as possible) and encourage them to join the process. Each organization, if invited, can explain the process to access agency services, as well as eligibility criteria. Some of these include, but are not limited to:
  - Department of Social and Health Services (DSHS)
    - Division of Developmental Disabilities (DDD)
    - Division of Vocational Rehabilitation (DVR)
    - Division of Services for the Blind
    - Mental Health Division, Regional Support Network
  - Department of Health (DOH)
  - Social Security Income (SSI)
  - Work Source
  - Employment Networks
- During the school years, focus the transition section of the IEP on a variety of vocational avenues in the community (situational assessments). An unsuccessful placement or job experience should be viewed as helpful in learning about the types of supports (training, conditions, and technology) the individual needs and their work preferences.
- Focus on abilities not disabilities. Do not assume the person is incapable of any task. Remember to structure trials using modification and supports in the community.
- Teach to individual strengths and search for a job with the maximum earning and benefits possible. This is needed because funding obtained from all sources including employment is the key for the individual to achieve their greatest community integration potential.
- In the final school year, transition goals will drive the IEP. The vocational portion of the IEP should focus on the acquisition and retention of a paid job in the community in such a way as to avoid loss of government benefits (e.g. SSI, Medicaid, Food Stamps, etc.)
- The high school should develop job skills and supports specifically designed or carved out to meet the individual's and employer's needs. Matching abilities with the needs of a business drives job development. It is helpful to answer the following questions during this process:

  (1) Which jobs match to the individual's abilities?

  (2) What weaknesses are liabilities to placement?

  (3) How can these challenges be overcome?
- While social activities are important to reinforce and to connect skills, be cautious not to weaken the transition plan by focusing primarily on social opportunities. Every student needs access to skill building opportunities for employment upon transition from school.

Currently the available support option for day activities after students leave school is employment. While there is an effort to figure out how to support transition students with reasonable day activities while they are looking for work, the goal both in federal and state rule and regulation for all students is employment (National Council on Disability, 2005). People with very severe disabilities face substantial obstacles both in terms of their ability to take advantage of social opportunities and employment opportunities. It is important not to sacrifice one or the other.

Employment is a way in which each person is provided with a natural way to be truly included in her or his community at least some of the time. It is difficult to reliably accomplish that in other specialized services, but there is evidence that it can reliably be accomplished within current spending levels for about 55-70 percent of the people who get employment supports. Employment provides a lot of service for a relatively small investment for most of the people supported.

Even for the small number of people that need very high levels of support, employment is very cost effective over the long-term. With a higher level investment, employment could be as effective for people with severe disabilities as it is for people with mild and moderate disabilities.

Reaching Out

- When determining an individual's learning or work potential, utilize assessments in the community that are meaningful to the individual in light of expected outcomes.
- Take supported risks. Sheltering and risk avoidance will not yield community supported employment. A simple adjustment to the work area or an additional piece of equipment is often all that is needed. The job developer working with the employer can facilitate such accommodations and open up possibilities never explored. Be aware and mindful of the individual's environmental conditions, socialization, sensory issues, etc.
- Investigate places in the community that offer volunteer experiences and use them for job sampling. These include:
    a. Public libraries
    b. Nursing homes
    c. Humane Society
    d. Public Television
    e. Hospitals
    f. United Way Agencies
    g. YMCA Programs
    h. Public Radio
    i. Local Universities
    j. Food Banks
- For places that do not offer volunteer experience, create a "contract" that you can "sell" to the employer and take to each site for the worker, employer and agency to sign. Document features will include (but need not be limited to):
    a. The job experience is a non paid experience.
    b. The job experience is a part of the individual's transition plan that drives the IEP goals and objectives.
    c. The job experience is not taking work away from regular employees.
    d. The individual is not guaranteed a job after the work experience.
    e. The individual is covered by worker's compensation under the school that is being represented.

Following work sampling, full time employment can be discussed so that this approach does not represent a barrier to employment.

Identifying and Maintaining Supports

- Learn about funding sources, how they work, what to do to acquire them and what each will offer (by 13-14 years old). Some agencies that provide or supervise funding include:

  a. Association of County Human Services

  b. DSHS-Division of Developmental Disabilities

  c. Social Security Administration (SSI)

  d. DSHS-Division of Vocational Rehabilitation

  e. Washington State Mental Health Division

  f. Washington State Department of Health

  g. Regional Support Networks.

- Develop knowledge and determine what supports will be needed and acquire them when needed, beginning with the planning of school to work transition until acquisition of a paid job in the community (preferably full time).

Strategies

- Promote the individual with tactics similar to those used when searching for employment to "open doors".

  Some "Sales/Marketing" tools might include:

  a. Résumé (including attendance records, awards)

  b. Videotape or pictorial of the individual working

  c. Letters of recommendations from supervisors/employers

  d. List of job skills and contributions to work environments

  e. List of supports they will have including transportation

  f. Performance reviews

  g. Productivity on various jobs

- Create partnerships with the business community.

  a. Invite business leaders to school, utilize family connections, expanded social circles (family owned business, churches, professional contacts, etc.).

  b. Go to community meetings and work sites. Discuss employing people with disabilities in supported employment.

  c. Encourage the business community to communicate about their specific employment needs.

d. Get statements from prior job experience supervisors. Relate positive and successful experiences from employers of individuals with disabilities.

- In some situations, it may be necessary to modify the goal to fade supports. Some individuals with ASD require long term or ongoing supports. Plans should then include identification of funding for these supports such as the Washington State Endowment Trust, Social Security Work Incentives, Individual Development Plans, County wide supports, etc.

Other Issues to Consider

- Training for all stakeholders should be ongoing. Use a variety of resources to train in areas such as job find, job development, job carving, self-employment/entrepreneur, job coaching, natural supports, behavior supports/strategies and modification, funding sources and uses, interviewing skills, employer expectations, (job descriptions, company rules, social etiquette, etc.).
- If the individual and his family desire, explore residential options that may be suitable for the full transfer to adult life to increase independence.

Agencies who can help with residential choices include:

a. DSHS-Division of Developmental Disabilities Case Manager

b. Residential Services Providers in city or county

c. Group Homes

c. Real Estate Firms

d. Home and Apartment publications

e. The Internet

f. Local Autism Support Groups

g. Community Alternative for People with Autism (CAPA)

It should be emphasized that residential services often involve long waiting periods and therefore should be applied for many years before they are needed.

- Recreation for people with disabilities is just as important as it is for their peers without disabilities. Access to the full range of recreational possibilities now exists in many communities, including vacation possibilities. Community recreational sites as well as the Internet can lead to exciting, person centered possibilities. Research indicates that individuals with disabilities can become isolated as they grow older.
- Due to lack of mobility, income, and social networks, individuals with disabilities may have difficulty making the right friends and meeting the right people to assure a quality adult life. Memberships in religious/cultural affiliations (e.g., church or synagogue), clubs, and recreational programs provide natural and ongoing support networks that can assist persons with disabilities in maintaining friendships throughout their life.

Practical Tips for Transitioning to Post Secondary Education after High School

Students with disabilities have the right and responsibility to pursue a job after high school which may require additional education or supports. When this occurs, the transition plan and IEP should support this vision. Preparation should then start at the beginning of high school for post secondary learning: such as post-secondary educational prerequisites like two years of foreign language, etc.

Under the Individuals with Disabilities Education Act (IDEA, 2004), the school is responsible for identifying and assessing individuals with disabilities and is mandated to provide appropriate educational instruction and related services. However, IDEA does not apply to individuals in postsecondary education, as the individuals themselves become responsible for many of the services that were once provided for them.

There are three pieces of legislation that impact postsecondary education. They are the Rehabilitation Education Act (REA) of 1973 (particularly section 504), the Family Educational Rights and Privacy Act (FERPA) of 1974, and the Americans with Disabilities Act (ADA) of 1990.

Section 504 of the Rehabilitation Act states that "no otherwise qualified individual with disabilities can be excluded from, denied the benefits of, or be discriminated against by any program receiving federal financial assistance." Although colleges and universities are not required to offer special education courses, subpart E requires both public and private institutions of higher education learning to make appropriate academic adjustments and reasonable accommodations (not modifications) to ensure individuals with disabilities can fully participate in the same programs and activities as non-disabled individuals.

ADA upholds and extends REA's civil rights protections to all public and private institutions regardless of whether they receive federal funds.

FERPA protects the confidentiality of individual's records at a postsecondary institution.

Although section 504 and ADA require equal access to post secondary education for individuals with disabilities, once the individual has been admitted, the individual is responsible for identifying himself as a person with a disability. He or she must also provide documentation that can trigger the appropriate accommodations. This accommodation process does not begin, however, until the individual contacts the college Office of Disability Services (ODS) and provides this documentation. Decisions regarding these accommodations then are made on an individual basis.

There are four major types of post secondary education:

a. Vocational/Technical Schools

b. Community Colleges (two year)

c. Colleges

d. Universities

Important Considerations for Postsecondary Transition

- Check with the postsecondary education facility to ascertain the requirements necessary to attend.
- Postsecondary options should be explored early in high school to select the proper course work.
- Choose a postsecondary program that provides the services and supports that will be needed by the individual after graduation.

- The individual and families should contact disability coordinators at prospective postsecondary programs to determine the services and supports which are available.
- The individual should receive training in self-advocacy on how to request needed accommodations and supports.
- Individuals should visit or audit classes from desired schools.
- University or college professors are not informed of an individual's disability, only of the necessary accommodation. Individuals and families may consider, if the professors require, additional information in order to effectively support individual learning.
- Electives during high school can be used as remedial courses to address academic areas of weakness.
- Individuals may wish to consider developing keyboarding skills to assist in assignment completion. Explore other assistive technology which might support individual learning and participation. e.g., computer software.
- Consider taking the SAT and ACT's tests as early as possible. Multiple chances to improve scores can be helpful.
- Take advantage of tutorials that are available to help with the SAT, ACT testing process.
- Take advantage of tutoring in high school that is available to help with difficult classes.
- Request that a representative from the university/college/vocational programs attend the IEP to assist in transition activities.
- Develop knowledge concerning dormitories, post-secondary residential housing, roommates, etc.

Chapter 8: Beyond Academics—Future Planning Issues

There is a positive new trend towards matching individuals with autism spectrum disorder (ASD) to work opportunities and job placement, building on the person's unique strengths and interests. A well written Individualized Education Plan (IEP) will include actions that lead to a good transition from high school to the adult world, including work. The IEP by itself is not enough, however, to assure that transition to adult life will be successful.

There are other aspects of planning for a child's future that families must address, including quality-of-life support for the individual when parents are not available, legal issues such as guardianship, financial planning to protect government benefits, and development of an advisory team and person centered action plan for the child, so that the child has plenty of support and ongoing therapies and interventions to live a healthy and meaningful life as an adult with autism.

Planning Issues:

1) **Quality of life**
2) **Legal**
3) **Financial**
4) **Government benefits**
5) **Age of majority; guardianship, partial guardianship, etc.**

Despite the growing number of persons with developmental disabilities in this country, few families have done any futures planning to address these issues. Like all of us, the child with a disability will be an adult longer than he or she will be a child, so futures' planning is critical. Planning for the futures of people with disabilities is something parents and caregivers must address – and the sooner the better. Whether the person with special needs is 4 or 40 years old, it is imperative that families create a plan.

Quality of Life

Quality-of-life issues are those everyday things that need to be in place for each of us to be comfortable in our daily lives. Addressing quality-of-life issues for our loved one with ASD requires decisions and information regarding:

- Where the person will live
- Religious affiliation
- Continuing education programs desired
- Employment preferences
- Social activities preferred
- Medical care required
- Behavior management practices
- Advocacy or guardianship needs
- Trustees identified for financial planning purposes
- Final arrangements desired

- Detailed instructions for assisting the person with the typical activities of daily living such as bathing, dressing, feeding, and toileting.
- Description of any special methods of communicating that only the immediate family knows and understands are included.

Lifestyle Planning—Written Instructions

Essential lifestyle planning is part of a process in which a family records what they want for the future of their loved one in a document sometimes called the "letter of intent." Although not a legal document, it is as important as a will and a special needs trust. The written instructions or letter of intent will include information on a variety of important issues, and can be used by others when parents are not available or unable to make sound decisions.

To guide decision-making for a document of intent, first start by developing a person centered plan for your child or loved one who has ASD. After developing a person centered plan, develop a letter of intent or written directive that discusses information regarding the needs and desires of the child with ASD. This document should address lifestyle, financial, legal, and government-benefit issues. Whether people with ASD function entirely on their own or need assistance, such a directive can provide instruction for their daily care, as well as provide guidance for unexpected contingencies.

Putting together a plan for the future should be guided through a process of learning how someone wants to live and for developing that future plan to help make it happen. It's also:

- A snapshot of how someone wants to live today, serving as a blueprint for how to support someone tomorrow.
- A way of organizing and communicating what is important to an individual in "user friendly", plain language that anyone can understand.
- A flexible process that can be used in combination with other person centered planning techniques.
- A way of making sure that the person is heard, regardless of the severity of his or her disability.

Lifestyle plans are developed through a process of asking and listening. The best essential lifestyle plans reflect the balances between competing desires, needs, choice, and safety.

Personal futures planning should be guided by attention to the following values:

- Placement of emphasis on interdependency among people.
- Remembering that as a group, strengths and talents are multiplied and weaknesses become less significant.
- Continuing to use the on going process for the person and circle of friends.
- Using a decision making process of goal setting and acquisition of supports.

Personal Futures Planning

Every person with a developmental disorder should have a plan for the future. Development of the written plan starts now at this point in time. How to develop the plan and proceed begins with the following list of ideas that address the large picture and considerations:

- Think about the process of setting short and long-term goals.
  - Identify and develop immediate next steps to reach the goals.
  - Keep an eye on the future and change in systems, health status, family status, etc.
  - What is the "now" for the individual?
  - Who is enrolled in the team?

- What are the roles of the team members?
- What does the person with ASD need to grow stronger?
- Identify steps for next month.
- Identify steps for three months, six months and one year.
- Assess the goals and plans at regular time intervals.

Some specific questions to look at and address in the written directive should cover:

- What are the person's preferences and needs related to bathing and dressing?
- Does the person have special dietary needs and requirements?
- Does the individual have any chronic medical conditions? Who monitors the medication?
- What is the person's daily schedule like?
- What leisure and recreational activities (music, computer, hobbies, sports) does the individual enjoy?
- What kinds of work activities does the person enjoy?
- Who are trusted friends and mentors?
- What supports can help the person to live with dignity, quality, self-esteem and security?

While most people realize they need to plan, for a variety of reasons many fail to do so. Some believe the task is overwhelming and don't know where to find qualified professionals who understand the needs and how to resolve concerns. Both the cost of professional services as well as privacy concerns can be an issue.

Establishing an Advisory Team

As families begin to develop a person centered plan and written directives, it is important to identify a group of people who will act as an advisory team. This should include, when possible, the person with ASD, family members, an attorney, a financial advisor, caseworkers, medical practitioners, teachers, therapists, friends, and anyone else involved in providing services to the individual. Having input from each of these individuals can help ensure that all parts of the plan are coordinated and complete.

Should parental support no longer be available, imagine how much easier and less traumatic it will be for the person with ASD and his or her care providers if they have detailed instructions immediately available, rather than having to figure things out on their own. What could take weeks or months to adjust to, could be shortened to a few days.

The ultimate goal of the letter of intent or written directive is to make the transition from parental care to independent or supported living or moving in with other family members as easy as possible, bearing in mind the comfort and security of the individual.

Use videotape to record the individual performing activities of daily living, including communicating.

Consider taping the individual having a meltdown and demonstrate the best ways of responding if that tends to be a relatively common occurrence.

Guardianship

As each child approaches age 18, parents need to research guardianship issues and decide which options are appropriate for the young adult. Guardianship is a legal determination that involves the child's ability to make decisions regarding their own affairs, including financial, medical, and educational decisions. If the parents do nothing, when a child turns 18, the parents lose the legal right to make decisions and sign legal documents for the child. Determining guardianship can sometimes be a difficult decision. Parents should discuss the issue with professionals and with other parents to learn about all the implications. For current information on guardianship in Washington, refer to the Arc of Washington State documents on future planning and guardianship at: **http://arcwa.org/publications.htm**.

Estate Planning

"Who will care when you are no longer there?" is an overwhelming question that parents of children with disabilities must address, but solutions and help are available.

Estate planning allows the family to state its wishes regarding the distribution of the family's assets and to appoint executors to settle the estate. In conjunction with estate planning, a trust can be established to provide supplemental funds for the individual with ASD, but in a way that maintains the individual's eligibility for government benefits. An estate planning team should include:

- Attorney
- Accountant
- Life underwriter/financial services provider
- Trust officer

A comprehensive estate plan should:

- Provide lifetime supervision and care if necessary
- Maintain government benefits
- Provide supplementary funds to help ensure a comfortable lifestyle
- Provide for management of funds
- Provide dignified final arrangements
- Avoid family conflict

Once the decision has been made to prepare a plan, find someone to help or hire a professional planner. Referral sources are available through governmental agencies, organizations, or local support groups. Use a life-plan binder. Place all documents in a single binder and notify caregivers and/or family where they can find it. At least once a year, review and update the plan and modify legal documents as necessary.

Establishing a Trust

Government entitlements play a key role in the lives of many persons with ASD by providing money and health care benefits under Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), Medicaid, and/or Medicare. A basic understanding of federal and state entitlement programs is essential in order to be sure that an individual gets all that he or she is qualified to receive. However, laws change, so it is crucial to hire professionals with up-to-date legal expertise. Special needs require special lawyers, or at the minimum an attorney familiar with all the concerns.

In establishing a trust, financial planning is used to determine the supplemental needs of the person over and above the government benefits they may receive. First, a monthly budget is established based on today's needs while projecting for the future. Then, by using a reasonable rate of return on the principal, the family identifies how much money is needed to fund the trust. The life expectancy of the person must be considered and then the need projected into the future using an inflation factor.

Once this is done, the family must identify the resources to be used to fund the trust. They may include stocks, mutual funds, IRAs, 401(k)s, real estate, and home or life insurance. Professional management for investing the assets may be done by the trustee, or the trustee may hire advisors.

Legal language has changed over time as state policies and legal decisions have evolved. When carefully drawn according to strict legal guidelines, trusts have been able to provide spending money to enhance the individual's daily life. Trusts can be a valuable tool for families, regardless of the size of their estate. Make sure that the attorney and other planning professionals under consideration for hire have specific expertise in planning for people with disabilities.

Information about trusts and special needs trusts is available from the Arc of Washington State at **http://arcwa.org/publications.htm**.

Chapter 9: Autism Awareness Training in the Community

This section describes the need for autism awareness training for a wide range of people including professionals, paraprofessionals, college personnel and students, families and community members who support individuals with Autism Spectrum Disorder (ASD). It includes the process of identifying stakeholders who need to be involved, areas that need to be addressed in training, and delineation of the multiple levels of training. Ongoing training is necessary to keep all stakeholders equipped with a rapidly changing knowledge base. With up-to-date information people will be able to collaborate more effectively and individuals with ASD will be able to access needed supports and services.

Types of training programs include pre-service training programs, in-service training programs, training for higher education faculty, and community and agency training. Identifying people who need training and what type of information they need should occur prior to their involvement with the individual with ASD. Training should focus on skill building as well as empowerment, problem solving, collaboration, and decision-making. Training should encompass the entire spectrum of ASD.

In planning any training program, it is strongly encouraged that trainers identify the needs of the audience and tailor training to meet the identified areas of concern. Educational and community systems as well as parents can often collaborate to offer comprehensive training opportunities. A variety of training approaches can be utilized. Given the individual characteristics involved with ASD, professionals and parents should have the opportunity to get hands-on, guided practice in order to best apply the information that they have been offered in a lecture format.

Effective approaches can include lectures, workshops, conferences (state, local, professional), group study/discussion, undergraduate and graduate coursework, mentoring, demonstrations, action research, dissemination of print and multimedia resources, interactive distance learning and internet access, hands-on experience, guided practice, observation, and consultations.

Subjects to be covered in training should include (but not be limited to):

- Characteristics of autism spectrum disorders.
- Best practices.
- Recognition and understanding of the implications of associated medical disorders, e.g., seizures, anxiety, attention disorder.
- Familiarity with a variety of assessment methods.
- The use of assessment to guide interventions.
- Self advocacy.
- ASD as it relates to individual's differences in learning and development.

- Adaptation of the curriculum.
- Motor planning.
- Writing and implementation of an effective behavior plan/behavior management.
- Enhancement of social interactions, cognition and perspective taking (Theory of Mind).
- Environmental supports to promote independence (Physical structure, individual schedules, etc.).
- Understanding of play, reciprocity and engagement.
- Available resources including relevant journals, films, books, articles, and videotapes as well as community resources like autism support groups, etc.

Everyone in the community who is part of the individual's team should identify training needs. This includes but is not limited to: direct service providers (teachers, instructional assistants, tutors), related service professionals (speech/language pathologists, psychologists, occupational and physical therapists, assistive technology specialist), administration staff (building principal, director of pupil personnel services), school community support staff (lunchroom personnel, recess monitor, bus drivers, volunteers, agency liaison), medical providers (physicians, nurses, dentists, hospital personnel, emergency and college campus health centers, therapists, etc.), first responders (law enforcement, firefighters, paramedics, emergency medical technicians), mental health service providers, parents and caregivers. Training and professional development plans are critical pieces of any effective program.

Washington State has training for law enforcement on an interactive CD entitled Interacting with *Persons with Developmental Disabilities and Mental Illness*. It is available to all law enforcement personnel on request from the Washington State Criminal Justice Training Commission at: **https://fortress.wa.gov/cjtc/www/training/dvd_training.html**.

The specific content for professional development should be determined on an individual basis. Training activities should be developed based on the designated needs of the professionals and community members and aligned with the needs of the individuals with ASD and their families.

Community persons should also participate in training regarding ASD. Included in this group are private and public providers, business owners, volunteer community service organizations (Kiwanis, Jaycees, Lions, Eastern Star), community business/organizations, (churches, libraries, YMCA, YWCA, Boys and Girls Clubs, Planned Parenthood, police and social work agencies, foster care providers, fire departments). Involve community workers who would typically touch the life of a person with ASD (grocery store workers, bus drivers, department stores, malls, pharmacies, restaurants, etc.).

Remember to also involve people/agencies who will be involved in providing adult services during and after transition to the community. Such groups as County Developmental Disabilities Human Services, DSHS Division of Developmental Disabilities case managers, Residential and Job Coaching vendors, Social Security, Medicaid etc., are examples of groups, as are local college administrators (Office of Disabilities) who deal with individuals with special needs in post-secondary settings.

Information in the field of ASD is constantly changing regarding both the nature of the disability and the methodologies and treatment practices. Best practice information continually evolves through research, so training should be an ongoing process.

Chapter 10: Advocacy

Levels of Advocacy

1. Advocating for children

The first step in becoming an advocate is learning to advocate for one's own child. Parents must learn about the diagnosis and what it means for their child's development, about the services and supports available to address their child's needs, and about how to work with professionals to ensure that their child's needs are met. These skills are learned by:

- Reading pertinent articles, books, and web sites.
- Participating in Individualized Educational Program (IEP) meetings and other service planning meetings.
- Talking with other parents who are willing to share what they know.
- Attending training and discussions offered by parent support groups and parent organizations.

2. Sharing information with other parents

The next level of advocacy is sharing information with another parent who needs it. This can be done informally in the hallway at school, in a parent support group, or over the phone. It can also be done more formally by leading a parent support group discussion on a topic or by providing a training session to a group of parents on a particular topic.

3. Supporting a parent in a service planning meeting

This level of advocacy includes a parent choosing to attend an IEP meeting with another parent to teach active parent participation. Learning the process from another adult who is familiar with the IEP process will help the new advocate to get needs addressed by learning to ask the right questions.

4. Participating in activities to influence how services are delivered

At this level parents advocate to change or influence the laws, regulations, and policies that affect the provision of services their child and other children with autism spectrum disorder (ASD) or other disabilities need. At that point, child advocacy becomes systems advocacy.

5. Encouraging a child to advocate for himself

It is important that parents of a child with autism work with the child to be his or her own advocate. Individuals with autism need to be encouraged to share their strengths and unique talents with others. This will allow members of the community to better understand what individuals with ASD can contribute to their communities.

Advocates are needed at all levels. Parent-to-parent support is critical for parents when all they have is a diagnosis and many more questions than answers. No one is more effective at answering those questions than another parent who has been in the same place. The Individuals with Disabilities Education Act (IDEA, 2004) acknowledges the importance of parents providing information to other parents by providing funding to support at least one parent training and information center run by parents in each state. Many parents have served in an advocacy role by helping to create this document to provide information to other parents.

When parents are educated about a family member's issues and the service systems, it is a natural step to take an active role in supporting other parents and in providing input to public agencies and policy makers about effective ways of supporting individuals with ASD. By communicating, parents can help create the schools and communities where the people they love can live, work and play.

Where to Advocate

There are many areas related to aspects of service delivery where parents' voices need to be heard. At the local school district or at the state level, the following are various issues that parents have identified as important.

Education

- Increasing the number of educators who understand the complexities of ASD.
- Placing students with ASD appropriately to best support their needs.
- Providing accommodations and or modifications tailored to the student's needs (not according to the student's label).
- Using research-based methods for instruction.
- Providing social skills training and development.
- Encouraging the full participation of children with ASD during the school day and in after-school activities.
- Providing effective transition services to ensure jobs and community living outcomes.
- Increasing partnerships with families.

Medical

- Increasing early screening and diagnosis opportunities.
- Educating medical personnel who may come in contact with children with ASD.
- Increasing the availability of specialists knowledgeable about ASD.
- Encouraging medical personnel to work in partnerships with families.

Social Services

- Increasing the number of providers who specialize in the unique needs of individuals with ASD.
- Making providers more easily accessible.
- Encouraging providers to work in partnership with families.

The Importance of Parents Supporting Parents

Parents can be the best resource for providing emotional support and helping another parent learn how to advocate for their child. Many organizations working to improve supports for those with disabilities originated with concerned family members exploring change. In every way possible, online or through parent support groups, the recommendation is for parents to stand with other parents and family members. It is one basic method of becoming involved in systems advocacy. In Washington, parent support is available through organizations such as Washington State Parent to Parent (**www.arcwa.org/parent_to_parent.htm**) and Washington State Fathers Network (**www.fathersnetwork.org**), Parent to Parent Power - dedicated to serving Asian parents of children with disabilities. (**www.p2ppower.org**), and others.

There are countless decisions to be made in the process of living with ASD. Since such decisions are individualized, families may find themselves choosing different treatment options or paths of education from those of other parents. They might be aligned with the views of a particular organization that is different from what other parents or family members prefer. The situation of each child is different and it would be easy to feel that there is little common ground with others.

It is unrealistic to expect everybody to agree on every choice. It is important to respect each family's choice and also stand with them to support policy changes or legislative changes that will make a difference in the community, the state, and the nation. A sizeable united voice cannot be ignored. Pointers for those interested in systemic advocacy include:

- Getting involved in efforts that impact the entire ASD community.
- Being publicly supportive of programs and services that may help any person affected by ASD, even if it does not affect each family directly.
- Respecting each individual's level of commitment to advocacy however small or large it may be.
- Giving first priority to being the best advocate possible for children, families, and adults.

Individuals with ASD are entitled to rights and services. Although the statement sounds simple and straightforward, many parents and family members know it can get complicated and be frustrating when trying to work with a system that does not understand a family member's needs. It is imperative that people with experience in ASD issues speak up as every person's experience will be unique. Often times people with a personal agenda urge law makers to make decisions that are not appropriate for the ASD community, such as mandating one specific type of intervention be used with all children with ASD. When there are various opinions and perspectives, the discussion will be rich and hopefully productive. Varied personal experiences will reflect the depth of the topics and a variety of solutions.

Advising a locally elected official on personal views is encouraged and a large part of the democratic process. Citizen participation provides representatives with the information they need from voters on what is important, and what is not working. This process is how decisions are made and answers are found for proposed policies, budgets, and legislation.

Various Ways to Advocate: Home, School, and Community

- Join an advocacy organization
- Advocate for a family member
- Advocate for other children
- Call, write, and e-mail legislators
- Vote every election

- Call a radio station to explain a position on a particular topic.
- Write a letter to the editor of the local paper.
- Hold a town meeting to discuss issues of interest.
- Attend a school board meeting to discuss concerns.
- Attend local and state social services board meetings to discuss issues.
- Join local or state committees that address what you are trying to accomplish.
- Visit a senator or state representative.
- Attend a rally at the State Capitol to raise awareness of ASD.

Tips for Talking with Leaders

- Always be respectful, courteous and professional.
- Thank leaders for the work on ASD issues.
- Be educated on the issues and differing perspectives.
- Write out and take along a well-thought-out agenda of discussion points and stick to it.
- Be brief and to the point.
- Ask for reasonable objectives.
- Refrain from being negative.
- Get to know contacts on their staff.
- Write letters thanking the staff and representatives for time and efforts.
- Offer to serve as the "autism expert."

Grassroots Advocacy

"Grassroots" advocacy refers to people working together to write letters, place calls, send e-mails, and visit officials to communicate ideas and opinions to government officials. Most of the time, efforts are concentrated to senators, representatives, and agency personnel. As a constituent, every person has the right to express knowledgeable opinions and advise elected officials about the issues of concern.

In Washington State, Autism Speaks has a government relations person dedicated to advocacy. Through the process of monitoring; insurance coverage for ASD interventions, laws passed in other states, and specific needs of citizens in Washington, Autism Speaks helps citizens create and influence state policies. More information can be found at the Autism Votes web site: **www.autismvotes.org**.

It is advised that people start small, perhaps with issues concerning a child or family member. This could be working with a child's teacher, school district and/or even school board on issues that arise regarding the educational progress or talking about residential group homes.

Awareness Campaigns

An awareness campaign is slightly different from advocacy work as it is geared toward educating a particular group of people or the general public. A good example of an awareness campaign is the annual April Autism Awareness Month promoted by Autism Speaks, the Autism Society of America (ASA), and the Autism Society of Washington (ASW). Each ASA chapter is encouraged to hold events, obtain proclamations, and distribute literature to the local community to inform them of the issues related to autism.

Local organizations often plan public events like runs or walks, community festivals, or open houses to help community members learn about autism and raise money for research or special projects. If interested in planning a local event, talk with other parents and family members to get their support. Also, contact a state organization like the ASW as they can link a person up with national organizations that may provide materials and guides for planning and staging events.

Ways to Spread Autism Awareness

Sponsoring a community-wide campaign is a major undertaking. However, there are many other, less time-consuming methods to spread awareness, including the following:

- Arrange to give a presentation to students at the local public school.
- Volunteer to educate local first responders (police, firefighters and paramedics) on how to handle individuals with ASD.
- Take time to educate family and relatives so they can become advocates for a child with ASD, as well.
- Write a letter to the editor of the local paper during Autism Awareness Month to outline the severity of the problem and what needs to be done.
- Wear the autism awareness ribbon, autism awareness bracelets or pendants every day.
- Stick an autism awareness ribbon magnet or bumper sticker on all vehicles.
- Distribute informational literature from national groups like ASA and Autism Speaks to local doctors, human service agencies, professionals, and therapists, etc.
- Hold a candidates' forum and invite several candidates to meet with families dealing with autism in their district to hear the stories and learn about the needs.

In 2005, the Washington State Legislature created the Caring for Individuals with Autism Task Force to develop a report for the legislature on services for persons with ASD in the state. The report contained 31 recommendations for improvements in services. Many of these recommendations, such as implementing new supports and service programs, require legislation to bring about change in systems.

It is important for individuals to become aware of what legislation is pending, both at the state and federal level. It is easy to learn about federal issues on the ASA web site at **www.autism-society.org**. Additionally, Washington state legislation can be accessed on the Autism Society of Washington web site at **www.autismsocietyofwa.org** and through The Arc of Washington State at **www.arcwa.org**. These web sites have e-mail "alert" systems that allow sign ups to receive legislation notices and recommendations for how to take action.

Additionally, it is important to have a voice heard by state and federal legislators. Identify the current state legislators by visiting **http://leg.wa.gov.** Click on "Find Your Legislator" and enter your address and zip code. It is easy to find federal legislators through a link on the Washington Legislature web site. Contact legislators and make them aware that a family member is on the spectrum. Describe the challenges faced by individuals with ASD and their families in Washington and the barriers encountered in getting needed services. Remember to always be constructive and considerate. The legislators represent you – and they want to hear from you!

- Families and professionals should be provided with opportunities to access information about ASD, education, transition, funding, agencies serving older individuals and adults, recreation options, respite, community activities, etc. Families should receive training to access and utilize these services/resources throughout the individual's passage through school to a job and adult life.
- Families should be given support to navigate the bureaucracies of education, medicine and other social services. Options could include a service coordinator, case manager, written lists of resources, referrals to local ASD groups, etc.

Prior to the age of eighteen, the individual's rights as an adult should be explained to both the individual and parent. The individuals' rights at the age of majority (eighteen years of age) need to be considered and addressed. Issues related to the need for guardianship may be discussed and facilitated by the professional team.

Families should be informed of their legal status throughout their child's life. This includes the parents' rights related to the IEP process, as well as the changes that take place at the child's eighteenth birthday (unless guardianship is obtained through the courts).

Appendix

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Appendix 1: Child Find Information

Child Find is the name of a continuous process of public awareness activities, screening and evaluation designed to locate, identify, and refer as early as possible all young children with suspected disabilities and their families who are in need of Early Intervention Program (Part C) or Preschool Special Education (Part B/619) services of the federal Individuals with Disabilities Education Act (IDEA, 1997, 2004).

In Washington State, the Child Find requirements for the Early Intervention Program are administered under the Department of Early Learning (DEL). Child Find Activities for ages three through 21 are under the lead agency of Office of Superintendent of Public Instruction (OSPI).

Washington Administrative Code (WAC) 392-172A-02040

(1) The school district shall conduct child find activities calculated to reach all students with a suspected disability for the purpose of locating, evaluating and identifying students who are in need of special education and related services, regardless of the severity of their disability. The child find activities shall extend to students residing in the district whether or not they are enrolled in school. Students attending private elementary or secondary schools located within the district shall be located, identified and evaluated consistent with WAC 392-172A-04005. Districts will conduct child find activities for infants and toddlers, consistent with the child find requirements of the lead agency for Part C of the act.

(2) Child find activities must be calculated to reach students who are homeless, wards of the state, highly mobile students with disabilities, such as homeless and migrant students and students who are suspected of being a student with a disability and in need of special education, even though they are advancing from grade to grade.

(3) The local school district shall have policies and procedures in effect that describe the methods it uses to conduct child find activities in accordance with subsections (1) and (2) of this section. Methods used may include but are not limited to activities such as:

   (a) Written notification to all parents of students in the district's jurisdiction regarding access to and the use of its child find system;

   (b) Posting notices in school buildings, other public agency offices, medical facilities, and other public areas, describing the availability of special education programs;

   (c) Offering preschool developmental screening;

(d) Conducting local media informational campaigns;

(e) Coordinating distribution of information with other child find programs within public and private agencies;

(f) Internal district review of students such as screening district-wide test results, in-service education to staff, and other methods developed by the school district to identify, locate and evaluate students including a systematic, intervention based, process within general education for determining the need for special education referral.

Early Intervention Program (Part C)

The Governor of Washington designated the Department of Early Learning (DEL) as the lead agency, with the primary responsibility for planning and implementing IDEA, Part C in Washington State. IDEA, Part C funds are used to enhance early intervention services for children, ages birth to three years, and their families, who meet Washington State's eligibility criteria. The federal legislation allows Washington State to request federal funds to:

- Implement a statewide, comprehensive, coordinated, interagency program of early intervention services for infants and toddlers with disabilities and their families;
- Facilitate the coordination of payment for early intervention services from federal, state, local and private sources, and enhance the capacity of the state to provide early intervention services.

As the lead agency, DEL delegates program management responsibilities to the Early Support for Infants and Toddlers (ESIT) program. ESIT manages and implements lead agency responsibilities for DEL including management of overall assurances, contracting and monitoring requirements.

ESIT facilitates the development of local and state interagency agreements and local early intervention plans. It assists contractors with implementation of policies and procedures and supports County Interagency Coordinating Councils (CICCs) to provide input to the State Interagency Coordinating Council (SICC) and intra/interagency working committees. ESIT develops training across all major disciplines around Part C implementation and service delivery and conducts ongoing monitoring of program operations, as necessary according to contractual need, and federal and state statutes.

Appendix 2: Washington's System of Services for Individuals With Autism Spectrum Disorder Ages Birth to Three

Early intervention services during the first years can make a significant difference in a child's life. Additionally, early intervention may also help parents understand their child's developmental growth. In Washington State the early learning program is referred to as the Early Support for Infants and Toddlers Program (ESIT) and is associated with a federal law called the Individuals with Disabilities Act (IDEA) (2004), Part C, Early Intervention Services.

IDEA encourages states to improve early intervention services. This directive provides guidelines for states in establishing and providing services for families with infants and toddlers with disabilities. Additionally, through annual maintenance of effort funding by the Washington State Legislature and Governor, the state is eligible to continue to apply for the federal dollars. This Part C funding amounts to approximately $8 million federal dollars to enhance services for eligible infants and toddlers. The state/federal partnership is essential in providing these services.

ESIT is located within the Department of Early Learning (ESIT) and works in collaboration with the Office of the Superintendent of Public Instruction (OSPI), the Department of Health (DOH), and the Department of Services for the Blind (DSB), to maintain a statewide system of early intervention services for children.

The ESIT system in each county is directed by the Local Lead Agency under the authority of DEL-ESIT Contracts. The local early intervention system is a collaborative program of child and family serving agencies including schools, health and human services, families, and other community providers and organizations. Each geographic area through coordination by the ESIT Local Lead Agency must maintain a County Interagency Coordinating Council to assure coordinated, collaborative, and comprehensive services.

The program helps families with infants and toddlers connect with resources they need. The program provides service coordination and ongoing specialized services to families of eligible children (age birth to three) with disabilities and developmental delays. When a child is identified with a developmental delay, the necessary early intervention services are identified through family resources coordination. Implementation and funding of services for each child and family are delivered as defined on an Individualized Family Service Plan (IFSP).

The IFSP is developed by the child's family and a team of professionals and includes outcomes, services, and methods to assist parents/primary care givers to support the development of the child. All children birth to three who meet the ESIT eligibility are entitled to early intervention services.

Under direction of DEL as outlined in the federally approved state definitions, policies, and procedures, the ESIT program will:

- Enhance the development of infants and toddlers with disabilities, to minimize their potential for developmental delay, and to recognize the significant brain development that occurs during a child's first three (3) years of life.
- Reduce the educational cost to our society, including our nation's schools, by minimizing the need for special education and related services after infants and toddlers with disabilities reach school age.
- Enhance the capacity of families to meet the special needs of their infants and toddlers with disabilities.
- Enhance the capacity of state and local agencies and service providers to identify, evaluate, and meet the needs of all children, particularly minority, low-income, inner city, and rural children, and infants and toddlers in foster care.
- Maximize the potential for individuals with disabilities to live independently in society.

The ESIT program has a comprehensive web site located at **www.del.wa.gov/development/esit/Default.aspx**.

Appendix 3: Special Education Ages Three Through Five

In accordance with state law, the Office of Superintendent of Public Instruction is responsible for making available educational services to preschool children with disabilities ages three to 21. Once it has been determined that the child has a suspected disability, the school district is responsible for completing an evaluation. Information collected through interview, observations, criterion-referenced/curriculum based and standardized assessments are reviewed and summarized to determine if the child is eligible for specially designed instruction and related services.

A team of individuals, including the child's parents, meet to review the results of the evaluation and develop an Individualized Education Program (IEP) for the child. The IEP includes, but is not limited to, a statement of present levels of performance, goals, objectives, evaluation criteria for each objective, special education services for each goal and the least restrictive setting in which services will be delivered.

In accordance with the IEP, service delivery options may include itinerant services and/or a special education center-based program. Itinerant services may be delivered in the home or to a child attending a public preschool, kindergarten, community-based preschool or child-care program.

A center-based special education program, located in an integrated setting or a separate facility, may be part-time or full-time. Each preschool education program provides an appropriate curriculum, which includes parent involvement and addresses developmental domains: adaptive, aesthetic, cognitive, communication, sensorimotor and social-emotional. With parent permission, a child is provided the services outlined on the IEP.

Children ages birth through five with characteristics associated with Autism Spectrum Disorder (ASD) may be found eligible for services without a formal diagnosis of ASD. Whether or not a child has been diagnosed with ASD, an IFSP or IEP will be developed that addresses the child's and family's needs.

For a more detailed look at Education and Autism in Washington State refer to the publication *The Education Aspects of Autism Spectrum Disorders*, 2008 available at **www.k12.wa.us/SpecialEd/pubdocs/Autism%20Manual.pdf**.

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Appendix 4: Least Restrictive Environment and Natural Environment

Least Restrictive Environment (LRE)

Least Restrictive Environment is the legislative terminology which is central to the Individuals with Disabilities Education Act (IDEA, 2004). The LRE concept has two parts:

1. Mandates that "schools must educate individuals with disabilities with children who do not have disabilities to the maximum extent possible."

2. States, "special classes, separate schooling, or other removal of children with disabilities from the regular educational environment occurs only when the nature or severity of the disability is such that education in regular classes with the use of supplementary aide and services cannot be achieved satisfactorily." Implicit in this statement is that children with disabilities be provided with an appropriate education. This is defined as an educational experience that allows the child to benefit from instruction.

The LRE is determined at least annually by the IEP team and is based on the child's unique service needs. Placement decisions should not be permanent or be based on administrative convenience. According to IDEA, no child can be excluded from any classroom solely because of needed modifications in the general curriculum. Likewise, in selecting the least restrictive environment, not every child with an IEP should automatically be placed in a "full inclusion" setting.

Consideration should be given to the quality of services. These guidelines are consistent with the current definitions and legal mandates for best practices in working with children with disabilities.

Natural Environment (NE)

IDEA, Part C requires states to ensure that, to the maximum extent appropriate, early intervention services to infants and toddlers under 3 years of age are provided in natural environments, such as the home and community settings in which children without disabilities participate. These settings include, but are not limited to home, preschool, nursery schools, Head Start programs, kindergartens, neighborhood school classrooms, child care, places of worship, recreational (such as community playgrounds and community events) and other settings that all children and families enjoy.

Services may be provided elsewhere only if early intervention cannot be achieved in a natural environment. In addition, each Individualized Family Service Plan (IFSP) must contain a statement of the natural environments in which services are to be provided and a justification of the extent, if any, to which the services will not be provided in a natural environment.

Instruction in the natural environment makes use of typically occurring events, activities, and consequences as a context in which to teach specific skills. The instructional context consists of routine events and everyday activities in a variety of settings. Typically, interactions between the child and adult are characterized as following the child's lead or capitalizing on the child's interest and engagement.

Effective practices should have a research base that documents positive results for young children with disabilities and also should reflect program characteristics that are valued by the field, such as

- A family-centered approach
- Compatibility with a multicultural and multiethnic perspective
- Developmentally and individually appropriate practices

Washington State's Infant Toddler Early Intervention Program Guidelines for Implementing Early Intervention Services in Natural Environments provides guidance to all individuals who comprise the state early intervention system in adapting and modifying services as necessary to meet the natural environment requirements of the IDEA, Part C (**www.del.wa.gov/publications/esit/docs/NaturalEnvironmentsGuidelines.pdf**).

Appendix 5: Inclusion

Inclusion is defined as providing specially designed instruction and supports for individuals with special needs on an IEP in the context of regular settings. Inclusion reflects a philosophy of acceptance, belonging and community. Inclusion does not simply happen when individuals are placed together in typical situations.

Inclusion education means that all individuals in a school, regardless of their strengths or challenges in any area, become part of the school community. It is part of a continuum of the Least Restrictive Environment (LRE) as defined by IDEA and its amendments. Individuals with ASD are included in the feeling of belonging among other individuals, teachers, and support staff.

This is accomplished through educational strategies designed for a diverse individual population and collaboration between educators so that specially designed instruction and supplementary aids and services are provided to all individuals as needed for effective learning.

For individuals with disabilities, inclusion accomplishes the following:

- Affords a sense of belonging to the family
- Provides a stimulating environment in which to grow and learn
- Enhances the feeling of being a member of the community
- Develops friendships
- Enhances self-respect
- Affirms individuality
- Provides peer models
- Provides opportunities to be educated with same-age peers

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Appendix 6: Functional Behavioral Assessment

The goal of a functional behavior assessment (FBA) is to identify those environmental factors that influence the display of appropriate and challenging behaviors. FBA can also identify the purpose or reinforcers that maintain behaviors by using systematic methods and empirical procedures. The information gleaned from this process is used to develop an effective intervention plan to increase the frequency of more desirable behaviors and decrease the frequency of undesirable behaviors.

When a functional behavioral assessment is necessary in school, the IEP team must take part in completion of the assessment. One member of the team must be a professional, trained and experienced in FBA and the development, implementation, and evaluation of behavior intervention plans.

The FBA typically involves interviews with service providers or others knowledgeable about the individual, completion of forms and checklists, and observing the individual in his or her natural environment. This information helps the team develop hypotheses as to the function(s) of the behavior of concern and the role of environmental factors that are influencing the behavior.

[Note: A more specialized and objective procedure can also be used. A functional behavioral analysis is the systematic manipulation of environmental antecedent variables and consequences to directly test hypotheses and establish a causal relationship between a behavior and factors that initiate, influence and maintain the behavior.]

The following problem-solving model was drawn largely from the *Ohio Model Policies and Procedures for the Education of Children With Disabilities (2000), Appendix F: Technical Assistance for Implementation of the Behavior Intervention*. It can be used to develop and evaluate the appropriateness of a behavior intervention plan.

Step 1: Discuss the vision or future planning for the individual.

- What is the long-term vision for the individual?
- What are the behavior barriers interfering with reaching or progressing toward the vision?

Step 2: Discuss present levels of performance.

- What strengths does the individual have?
- Where is the behavior most or least likely to occur?
- How often does the behavior occur?
- How long does the behavior (event) last?
- How long a period of time typically exists between a request and when the individual begins to respond?

- How extreme is the behavior?
- For each occurrence, with whom is the behavior most/least likely to occur?
- What is the general response of others to the behavior?
- How does the individual react to others' responses?

Step 3: Write a statement clearly describing the behavior of concern, taking into account information obtained in Step 2.

Step 4: Collect additional data to fully and completely understand the nature and cause of the behavior of concern.

- What usually happens in the individual's environment, instruction, and relationships just before and just after the behavior of concern occurs?
- What other information is relevant to the behavior of concern (e.g., medication, medical condition, sleep pattern, diet, schedule, relationships)?
- How does the individual typically communicate wants and needs?
- What is the individual's behavior history?
- What interventions and modifications have been found to be successful and unsuccessful with regard to the behavior of concern?
- What are the academic, curricular, self-care, and social skills that make up the individual's profile?
- For what purpose(s) does the individual use the behavior of concern (e.g., power, control, avoidance/escape, attention)?
- What is the individual trying to communicate with the behavior?

Step 5: Identify and prioritize the needs of the individual for the IEP (or for the behavior plan if the individual does not have an IEP) by considering the following:

- Which behaviors are likely to cause harm to the individual or others?
- Which behaviors impede the learning of the individual or others?
- Which behaviors occur most frequently?
- Which behaviors are most intense?
- Which behaviors, when effectively addressed, will have a positive impact on other behaviors of concern?

Step 6: Identify measurable goals, objectives, and assessment procedures

- What behavior could replace and serve as a more acceptable alternative to the behavior of concern?
- Does the replacement behavior serve the same function to the individual as the behavior of concern?
- Will mastery of the goals/objectives enable the individual to more fully participate in the general education curriculum?
- Have positive intervention strategies been demonstrated to be ineffective prior to the proposed use of more restrictive intervention procedures?

- Are the goals/objectives stated in terms that the individual understands?
- Do the goals/objectives help build confidence and competence, promote independence and self-advocacy, and help develop personal responsibility?
- Were cultural differences taken into account when the goals/objectives were developed?
- Can the goals/objectives in the behavior plan be generalized to other settings?

Step 7: Identify measurable goals, objectives, and assessment procedures

- Have criteria been established for each goal/objective for measuring success in relationship to baseline data?
- What methods will be used to evaluate whether there is an increase in the use of replacement behavior and decreased use of the behavior of concern?
- Has the IEP team considered how frequently it will evaluate progress based on the frequency, intensity, and severity of the behavior of concern?

Step 8: Identify needed services

- What environmental changes need to be considered?
- What accommodations, intervention techniques, and supports are needed for the individual to learn and use the replacement behavior?
- Do the interventions rely on logical consequences instead of punishments?
- If necessary, have several interventions been designed to meet the diverse and unique needs of the individual?
- Does research support using the selected interventions with the behavior of concern?
- How will stakeholders (including family members) be trained and supported in implementing the behavior intervention plan?
- Can the plan be held up to ethical standards?

Step 9: Determine the least restrictive environment

- Are the replacement behaviors outlined in the intervention plan appropriate for the environments in which the plan will be implemented?
- If the IEP team has determined that the individual will be removed, have strategies been included in the behavior intervention plan for re-introducing the individual to the regular educational environment?
- Has the IEP team considered interventions that will increase the likelihood that the individual educational environment? Will be educated with non-disabled peers?
- Have interventions been tried and documented prior to placement in a more restrictive environment?

Step 10: Periodically evaluate outcomes, taking into account the following questions

- Was the plan effective in increasing the use of the replacement behavior and decreasing the behavior of concern?
- Were the interventions appropriately applied and documented?
- Is the behavior intervention plan being implemented as designed?
- Were adjustments made as needed during the implementation phase of the plan?
- Were parents, staff, the individual, and outside agencies involved in the review and revision of the behavior intervention plan?
- Has the intervention plan been implemented for a sufficient length of time?
- Has the intervention plan been continued, revised, or eliminated as a result of the periodic review?

Appendix 7: Instructional Accommodations and Modifications

The purpose of accommodations and modifications are to facilitate the individual's full participation in the general education curriculum. These may range from minor accommodations to major instructional modifications. Critical information about the individual's learning style, academic abilities, and sensory motor skills will guide the use of the following.

A. Time

Change the amount of time allowed for learning, testing and task completion. This includes time for breaks during the task or activity.

Examples:

- Take home class work to finish.
- Give more time to complete part or all of a test.
- Remove the "timed" portion of an activity.
- Allow quick "stretch breaks" during an activity.
- Build in planned breaks with no requirement for completion at that time, in order to prevent individuals from spending too much time on an activity, becoming frustrated and inattentive.

B. Size / Amount

Change the required amount of items that the individual is expected to complete.

Examples:

- Cut the worksheet in half.
- Place a "stop sign," red line, or some other indicator on the sheet to indicate that the individual is done at that point.
- Allow the individual to choose "X" amount of problems/items to complete from the larger amount.
- Allow the individual to decide if he should complete 5, 6 or 7 items of the 10 items (building in choice).
- Start a new concept by completing only one or two items, the next time three, then four, etc., as the individual's confidence and skill improves.
- Allow the individual to do more items than required if it is an area that he enjoys. Give extra credit for those items to help balance a time when he is not as successful with an activity.

C. Participation

Adapt the extent to which an individual may be involved in the task or activity by allowing the individual to use his strengths and interests.

Examples:

- The individual may type the answers that his group tells him to type.
- The individual may glue the pictures on the page that have been placed in the correct order, while other individuals are deciding order.
- The individual may hold the map while others point to various locations.
- The individual may pass out the reading books to each classmate and choose who will read while others do the actual reading.
- The individual holds the "strands of DNA" (string) while the other individual decides in what order the "molecules" (gumdrops) are placed.
- The individual listens in reading group while others read.
- The individual that has difficulty with auditory comprehension reads while others listen and is then excused to complete a hands-on task.
- A vocational activity may include a variety of individuals with different strengths. In one shopping activity there may be an opportunity for the individual to:

  a. Write the list
  b. Decide what to put on the list
  c. Decide the approximate amount of money needed and to count out that amount
  d. Give directions to the store
  e. Read the list
  f. Cross off the items as collected
  g. Push the cart
  h. Decide which line is shortest/fastest at the checkout
  i. Greet store employees who are familiar
  j. Count out the necessary money
  k. Bag groceries
  l. Carry the bags
  m. Count to be sure everyone is accounted for when time to go

D. Input

Provide a variety of ways that instruction is delivered to the individual to maximize the individual's learning style/strength.

Examples:

- Use an overhead projector to note the main facts or important concepts that the individual is to remember.

- Use an amplification system to improve the individual's ability to understand and attend to the verbal instruction.
- Allow for small group activities that support the general concepts being taught. In this case, the focus is on the information generated to the group vs. an end product. For example, the individuals may work in a small group and discuss specific examples of dairy, meat, vegetables, fruits, etc. from their daily meals.
- Provide a "designated note taker" or Xerox copy of other individuals or teacher's notes.
- Provide a printed outline with videotapes and filmstrips.
- Provide a print copy of assignments or directions which are written on the blackboard for the individual that cannot easily shift attention from board to paper.

E. Output

Modify the way an individual is required to respond to instruction or show knowledge of instructional material.

Examples:

- Allow for fill-in-the-blank answers for the individual who has difficulty with handwritten assignments.
- Allow the individual to use a keyboard, computer, or label-maker instead of handwriting on assignments.
- Allow the individual to respond verbally instead of on paper.
- Allow the individual who has difficulty working in groups to "instant message" with the teacher or individuals to decrease anxiety.
- Allow the individual to build models or other hands-on activities to show knowledge instead of written or oral reports.

F. Difficulty

Adapt the skill level required, the type of problem presented, or how the individual may approach learning the required materials.

Examples:

- Allow the individual to have "open-book test."
- Allow the individual to use a calculator.
- Provide the individual with the correct numbers and functions to use with a story problem.
- Break problems or tasks into smaller, more easily understood steps. For example,
  - Provide the individual with a visual list of items that are necessary in order to accomplish an academic task (calculator, pencil, paper, book, and ruler), rather than just a direction to "get ready for math."
  - Instead of presenting a large number of food items and directing the individual to categorize items as fruit, vegetable, dairy or meat; ask the individual to locate one category of items at a time, providing a picture, if necessary, or simply ask the individual to match the food item to the name.

G. Level of Support

Increase the amount of personal assistance that the individual receives.

Examples:

- Allow for a peer to assist in completing tasks or understanding materials.
- Provide educational assistant to explain tasks, modify the materials, provide environmental supports or modify the environment.
- Provide additional tutoring outside of the specific educational instruction to assist in understanding the material or formulating responses.

H. Modified Curriculum

Provide different instruction, materials and goals for an individual.

Examples:

- An individual may learn computer/keyboarding while others take a language test or work on a language activity.
- An individual may cut out items from a magazine and create a picture book of healthy foods while other individuals are writing a creative story.
- An individual may have work experience in a local record store while others are taking algebra or calculus classes in the school.
- An individual may create his personal schedule for the day while others are participating in "calendar and weather" during the class group activity.
- An individual may take a morning walk as part of a "sensory diet" while others are reviewing the homework assignment and making corrections.

Appendix 8: Education Best Practice Guideline Checklist

The following guidelines can be used by both parents and educators to address the unique needs of students with autism. This list is not intended to be included in every plan for every child. It is intended to be a starting point for discussion by the planning team when designing an individualized plan.

Student Planning Goal / Objective	Now	Not Now
1: Extended Educational Programming		
Extended Day and Extended School Year. (NOTE – these are distinct and need to be clearly defined.) 1. Duration and programming to be based on individual needs. 2. Extended day should to be different from In-Home Training. 3. Determine eligibility criteria based not solely on likely regression, but also on a needs assessment of the following areas: behavior, social skills, communication, academics, and self help skills. 4. Should be available to all eligible students; not to be determined by district availability funds/staff. 5. To include variety of structural programs/settings. 6. Services should be linked to IEP objectives and goals.		

Student Planning Goal / Objective	Now	Not Now
2: Daily Schedules Reflecting Minimal Unstructured Time		
Individualized daily schedule reflecting minimal unstructured time and active engagement in learning activities to the maximum extent possible. 1. Flexibility within routines to adapt to individual skill level. 2. Learning activities should be based on IEP goals and objectives and related educational activities. 3. Engagement time may include lunch, snack, and recess. 4. Consideration should be given to aiding students with changes in routine schedules such as, field trips, substitute teachers, and pep rallies.		

Student Planning Goal / Objective	Now	Not Now
3: In-Home and Community-Based Training		
Include training and IEP goals and objectives to assist in acquisition and generalization to the home and community setting (appropriate social interaction skills including social and behavioral skills) based on needs assessment. (NOTE: Define In-Home and Community-Based training.) 1. Strategies to facilitate maintenance and generalization (home to school, home to community, school to home, school to community). 2. Consideration should be given to guidelines for the qualifications of the In-Home trainer.		

Student Planning Goal / Objective	Now	Not Now
4: Positive Behavior Support Strategies		
Positive Behavior Supports include Functional Behavior Assessment (FBA), antecedent manipulation, teaching replacement behaviors, reinforcement strategies, data based decisions. Behavior Intervention Plan developed and maintained based on a Functional Behavioral Assessment using current data collection of target behaviors. 1. Considerations and guidelines should be written for the person who is performing the FBA. 2. Behavioral programming is structured across school, home and community-based settings.		

Student Planning Goal / Objective	Now	Not Now
5: Futures Planning for Integrated Living, Work, Community and Educational Environments		
Considered for all students with ASD, at any age 1. Consider skills necessary to function in all environments post graduation. 2. Consider skills necessary to function in all environments 3 years hence. 3. Consider skills necessary to function in all environments for current year.		

Student Planning Goal / Objective	Now	Not Now
6: Parent / Family Education, Training, and Support		
Parent/family education, training, and support are designed to provide the parent/family with skills/techniques needed in order to help their child become successful in the home/community setting. Parent training is provided by qualified personnel with experience in autism and may include but is not limited to: information regarding parent support groups, workshops, videos, conferences, direct consultation, materials, separate and distinct from in-home training to increase the parent's knowledge of specific teaching and management techniques, curriculum information, provide information related to the child's disability and available resources, and facilitate parental carryover of in-home training. Strategies can include behavior management, setting a structured home environment, or communication training. Parents are active participants in promoting the continuity of intervention across all settings based on IEP.		

Student Planning Goal / Objective	Now	Not Now
7: Staff-to-Student Ratio		
Staff-to-student ratio appropriate to identified activities and as needed to achieve progress on social, behavioral, and/or academic IEP goals and objectives. The team may determine ratios based on the following considerations: 1. Level of learning (acquisition, fluency, maintenance, generalization). 2. Priority given to work towards individual independence by fading dependence on 1:1 ratios. 3. Developmental level of the student. In the case of young children (developmental level 0-8 years) no more than two children with autism spectrum disorder per adult as determined by results of adaptive behavior evaluations. 4. Behavior needs. 5. Accommodations across all settings. 6. Transitions within the school day. 7. Teaching activities.		

Student Planning Goal / Objective	Now	Not Now
8: Teaching Strategies		
Teaching strategies shall be based on peer reviewed and empirically validated evidence-based practices/methodologies for students with autism. At this time the science heavily favors, but is not limited to those based on the science of applied behavior analysis, defined as the application of behavioral principles for the benefit of the learner and includes simultaneous evaluation of the effect of these applications. The following instructional strategies should be considered: ◆ Discrete-trial training ◆ Visual supports ◆ Structured learning ◆ Augmentative and Alternative Communication ◆ Social skills training Implementation of the instructional strategies should be reflected in the IEP. The following will be considered: ◆ How will this strategy be implemented? ◆ When and by whom?		

Student Planning Goal / Objective	Now	Not Now
9: Communication		
Communication intervention, which considers language forms and functions that enhance effective performance across settings. Strategies may include, but are not limited to: • Augmentative and Alternative Communication • Milieu, incidental, or naturalistic teaching • Verbal Behavior • Pragmatics • Conversation skills		

Student Planning Goal / Objective	Now	Not Now
10: Social Skills Support		
Consideration will be given to the following areas: 1. Appropriate social skills assessment and curriculum. 2. Instruction provided by highly qualified service providers. 3. Use of trained peer facilitators such as, but not limited to, circle of friends. 4. Strategies may include but are not limited to video modeling, Scripts training, social stories, and role playing. 5. Support to be provided across all settings.		

Student Planning Goal / Objective	Now	Not Now
11: Professional Educator / Staff Support		
Professional development will be provided for all personnel who work with the student to assure the correct implementation of the techniques and strategies as determined by the IEP.		

This checklist was developed through the work of the Texas Autism Rule Study Committee, a committee comprised of parents, Autism providers (Board Certified Behavior Analysts), school principals, and Texas education agency representatives. It was shared through the efforts and courtesy of the committee and Arzu Forough (2007).

Appendix 9: Implications for the Education System

The goal of our special education system for people with disabilities, including those with the most severe disabilities, should be to offer them the greatest potential to be fully employed in the community, working forty hours/week with benefits, at a wage level per hour that allows them to live a high quality life (above the poverty level) and reach for their full potential. This will take a different approach and significant partnering between the medical, school and adult service delivery communities.

In order for the employment situation to improve in Washington, people with autism spectrum disorder (ASD) must be better identified and the school to work transition approach individualized.

Implications

Due to education's primary role in the lives of children with autism, the following points are critical:

a. Improved timelines of identification services at an early age of individuals with ASD in Washington.

b. The employment focus starts at the earliest stages of special education and have that be reflected by the development of vocational skills and an employment outcome emphasis.

c. Ensure that parent, guardian, care givers, educators-administrators, and adult service provider agencies have ongoing training in the process of vocational transition from school to work.

d. Schools, Vocational Rehabilitation agencies, and Social Security Administration should collaborate to assist families in the understanding and utilization of work incentives such as, but not limited to, Plan to Achieve Self-Support (PASS)/Impairment Related Work Expenses (IRWE)/Individual Earned Income Exclusion.

e. Recognize that successful ongoing retention of a job in the community, particularly for people with ASD, will require ongoing supports, not the typical "time limited" ones.

f. Realize that the school to work transition planning process time for people with ASD is intensive and intentional.

g. The school to work transition planning process should begin, by law, no later than age sixteen. With that said, it would be advantageous to begin the process before age 16 (IDEA, 2004). It should encompass a job goal working back with objectives each year until the present time (backward planning). This should include situational assessments and active work experiences with needed supports. This process should lead toward paid work at the end of the school years when the entitlement to supports ends.

h. Special education programs should be evaluated on the effectiveness of individual post school employment outcomes in terms of:

- Hours worked per week in the community (not sheltered setting).
- Average hourly earnings.
- Monthly earnings versus the Substantial Gainful Activity Level (SGA).
- The retention time of the job.
- The ability to get benefits as well as earnings to reduce government dependency.
- Their ability to integrate choices of the person with disabilities into the employment outcome.
- The number of individuals who are actually employed upon graduation.
- The level of financial/social/residential independence e.g., full integration into the community with needed supports.

i. Schools collaborate with partners in this process including adult services agencies who will engage in the "hand off" process as well as government and funding agencies who will provide fiscal or resource supports.

j. Ensure the Individual Education Plan (IEP) team concept is comprehensive to include these other groups at appropriate times.

k. Recognize that individuals with ASD will require particular help with, but not limited to:

- Behavior support and self regulation of behavior
- Socialization skills
- Communication skills
- Ongoing supports to reflect the individual needs

Appendix 10:
Choosing Treatment Options

Questions for Parents or Caregivers to Ask Regarding Specific Treatments and or Programs:

- What characteristic behaviors of autism spectrum disorder (ASD) am I trying to target?
  - Does the treatment that I am considering target these characteristic behaviors?
- Are there any harmful side effects associated with this treatment?
- What positive effects of treatment would I hope to see?
- What are the short-term and long-term effects?
- Can this treatment be integrated into my child's current program?
- What is the cost of treatment?
- Will my insurance company pay for the treatment?
- How much time does the treatment take?
  - Can I realistically devote the time required to the treatment?
- Has this treatment been validated scientifically?
- Have I researched the treatment?
- Was I able to interview other parents and professionals about the treatment?
  - If so, list stated pros, cons, and other areas of interest.
- Do proponents of the treatment claim that this procedure can help nearly everyone?
  - If so, this should be seen as a "red flag" to slow down and be more careful in consideration of this technique.
- What do my pediatrician and other professionals involved with my child think about the treatment's appropriateness?

Points for Parents or Caregivers to Ponder when Considering Participation in a New Intervention and or Program:

- Does the program or therapy and anticipated outcomes meet the unique strengths, challenges, or goals for my child?
  - What are the anticipated outcomes of this intervention?
  - What positive changes can I expect to see in my child's behavior, communication, eating, sleeping, learning, etc.?
  - Do these outcomes address what I see as the unique strengths, challenges or goals for my child?
  - Do these outcomes match my expectation or goals for my child?
  - Are there any potentially negative outcomes of the intervention?
- How will these goals or outcomes be evaluated?
  - How will I know if my child is making progress toward desired outcomes?
  - What method will be used to evaluate child progress?
  - How often will we evaluate child progress?
  - Who will conduct the evaluation?
  - How long will we continue until a change can be made in the intervention?
- What are the potential risks?
  - Will my child face an immediate risk?
  - Are there any risks for other family members?
  - Are there any activities, foods, etc. that will be restricted?
- What is the back-up plan if we choose to discontinue this intervention?
  - Is there any risk of discontinuing the intervention?
  - What kind of early intervention services will my child receive if we decide to stop the intervention?
- Is there a good fit between the intervention and our family life?
  - Can we do what will be asked of us?
- Have I received information about this from a variety of sources?
- Is this intervention published in peer-reviewed journals?
- Are there alternatives that are: less restrictive? Better researched?
- How will these new interventions be combined with strategies and therapies that we are already using with my child?

Appendix 11: American Academy of Pediatrics - Clinical Guidelines on Autism

In late 2007, Doctors Chris Johnson and Scott Myers from the Council on Children with Disabilities authored two autism clinical reports detailing information on autism and care management facts for pediatricians and care providers. Due to the size of the documents (approximately 75 referenced pages) only the abstracts of the studies are presented.

Identification and Evaluation of Children with Autism Spectrum Disorder

Clinical Report Abstract

Autism spectrum disorders are not rare; many primary care pediatricians care for several children with autism spectrum disorders. Pediatricians play an important role in early recognition of autism spectrum disorders, because they usually are the first point of contact for parents. Parents are now much more aware of the early signs of autism spectrum disorders because of frequent coverage in the media; if their child demonstrates any of the published signs, they will most likely raise their concerns to their child's pediatrician. It is important that pediatricians be able to recognize the signs and symptoms of autism spectrum disorders and have a strategy for assessing them systematically.

Pediatricians also must be aware of local resources that can assist in making a definitive diagnosis of, and in managing, autism spectrum disorders. The pediatrician must be familiar with developmental, educational, and community resources as well as medical subspecialty clinics. This clinical report is 1 of 2 documents that replace the original American Academy of Pediatrics policy statement and technical report published in 2001. This report addresses background information, including definition, history, epidemiology, diagnostic criteria, early signs, neuropathologic aspects, and etiologic possibilities in autism spectrum disorders.

In addition, this report provides an algorithm to help the pediatrician develop a strategy for early identification of children with autism spectrum disorders. The accompanying clinical report addresses the management of children with autism spectrum disorders and follows this report on page 1162, available at **www.pediatrics.org/cgi/content/full/120/5/1162**. Both clinical reports are complemented by the toolkit titled *Autism: Caring for Children With Autism Spectrum Disorders: A Resource Toolkit for Clinicians*, which contains screening and surveillance tools, practical forms, tables, and parent handouts to assist the pediatrician in the identification, evaluation, and management of autism spectrum disorders in children (Johnson, C. P., Myers, S. M., 2007).

The full clinical report is available from the American Academy of Pediatrics at **http://aappolicy.aappublications.org/cgi/content/full/pediatrics;120/5/1183**.

American Academy of Pediatrics Clinical Guidelines on Autism
Management of Children With Autism Spectrum Disorders

Clinical Report Abstract

Pediatricians have an important role not only in early recognition and evaluation of autism spectrum disorders but also in chronic management of these disorders.

The primary goals of treatment are to maximize the child's ultimate functional independence and quality of life by minimizing the core autism spectrum disorder features, facilitating development and learning, promoting socialization, reducing maladaptive behaviors, and educating and supporting families. To assist pediatricians in educating families and guiding them toward empirically supported interventions for their children, this report reviews the educational strategies and associated therapies that are the primary treatments for children with autism spectrum disorders.

Optimization of health care is likely to have a positive effect on habilitative progress, functional outcome, and quality of life; therefore, important issues, such as management of associated medical problems, pharmacologic and nonpharmacologic intervention for challenging behaviors or coexisting mental health conditions, and use of complementary and alternative medical treatments, are also addressed. (Johnson, C. P., Myers, S. M., 2007).

The full clinical report is available from the American Academy of Pediatrics at **www.aap.org/pressroom/issuekitfiles/ManagementofChildrenwithASD.pdf**.

Appendix 12: American Academy of Neurology and Child Neurology Society - Guideline Summary for Clinicians

Screening and Diagnosis of Autism

This is a summary of the American Academy of Neurology (AAN) and Child Neurology Society (CNS) guideline on screening and diagnosis for autism. This practice parameter reviews the available empirical evidence and gives specific recommendations for the identification of children with autism. This approach requires a dual process:

1) Routine developmental surveillance and screening specifically for autism to be performed on all children to first identify those at risk for any type of atypical development, and to identify those specifically at risk for autism; and

2) To diagnose and evaluate autism, to differentiate autism from other developmental disorders.

Level One: Routine developmental surveillance screening specifically for autism

Good Evidence Supports:

1. Developmental surveillance should be performed at all well-child visits from infancy through school-age, and at any age thereafter if concerns are raised about social acceptance, learning, or behavior (Level* B).
2. Recommended developmental screening tools include the Ages and Stages Questionnaire, the BRIGANCE® Screens, the Child Development Inventories, and the Parents' Evaluations of Developmental Status (Level B).
3. Because of the lack of sensitivity and specificity, the Denver-II (DDST-II) and the Revised Denver Pre-Screening Developmental Questionnaire (R-DPDQ) are not recommended for appropriate primary-care developmental surveillance (Level B).
4. Further developmental evaluation is required whenever a child fails to meet any of the following milestones (Level B): babbling by 12 months; gesturing (e.g., pointing, waving bye-bye) by 12 months; single words by 16 months; two-word spontaneous (not just echolalic) phrases by 24 months; loss of any language or social skills at any age.
5. Siblings of children with autism should be carefully monitored for acquisition of social, communication, and play skills, and the occurrence of maladaptive behaviors. Screening should be performed not only for autism-related symptoms but also for language delays, learning difficulties, social problems, and anxiety or depressive symptoms (Level B).

6. Screening specifically for autism should be performed on all children failing routine developmental surveillance procedures using one of the validated instruments—the CHAT or the Autism Screening Questionnaire (Level B).

7. Laboratory investigations recommended for any child with developmental delay and/or autism include audiologic assessment and lead screening (Level B). Early referral for a formal audiologic assessment should include behavioral audiometric measures, assessment of middle ear function, and electrophysiologic procedures using experienced pediatric audiologists with current audiologic testing methods and technologies (Level B). Lead screening should be performed in any child with developmental delay and pica. Additional periodic screening should be considered if the pica persists (Level B).

Level Two: Diagnosis and evaluation of autism

Strong Evidence Supports:

1. Genetic testing in children with autism, specifically high resolution chromosome studies (karyotype) and DNA analysis for Fragile X (FraX), should be performed in the presence of mental retardation (or if mental retardation cannot be excluded), if there is a family history of FraX or undiagnosed mental retardation, or if dysmorphic features are present (Level A). However, there is little likelihood of positive karyotype or FraX testing in the presence of high-functioning autism.

2. Selective metabolic testing (Level A) should be initiated by the presence of suggestive clinical and physical findings such as the following: if lethargy, cyclic vomiting, or early seizures are evident; the presence of dysmorphic or coarse features; evidence of mental retardation or if mental retardation cannot be ruled out; or if occurrence or adequacy of newborn screening at birth is questionable.

Good Evidence Supports:

1. There is inadequate evidence at the present time to recommend an EEG study in all individuals with autism. Indications for an adequate sleep-deprived EEG with appropriate sampling of slow wave sleep include (Level B) clinical seizures or suspicion of subclinical seizures, and a history of regression (clinically significant loss of social and communicative function) at any age, but especially in toddlers and preschoolers.

2. Recording of event-related potentials and magnetoencephalography are research tools at the present time, without evidence of routine clinical utility (Level B).

3. There is no clinical evidence to support the role of routine clinical neuroimaging in the diagnostic evaluation of autism, even in the presence of megalencephaly (Level B).

4. There is inadequate supporting evidence for hair analysis, celiac antibodies, allergy testing (particularly food allergies for gluten, casein, candida, and other molds), immunologic or neurochemical abnormalities, micronutrients such as vitamin levels, intestinal permeability studies, stool analysis, urinary peptides, mitochondrial disorders (including lactate and pyruvate), thyroid function tests, or erythrocyte glutathione peroxidase studies (Level B).

This guideline summary is evidence-based. The AAN uses the following definitions for the level of recommendation and classification of evidence. *Definitions for strength of the recommendations: **Level A:** Established as effective, ineffective or harmful, (or established as useful/predictive or not useful/predictive) for the given condition in the specified population. **Level B:** Probably effective, ineffective or harmful (or probably useful predictive or not useful/predictive) for the given condition in the specified population. **Level C:** Possibly effective, ineffective or harmful (or possibly useful predictive or not useful/predictive) for the given condition in the specified population. **Level U**: Data inadequate or conflicting. Given current knowledge, treatment (test, predictor) is unproven.

Information provided by the American Academy of Neurology. (2006). Guideline Summary for Clinicians, www.aan.com/globals/axon/assets/2605.pdf

Appendix 13: Tips for Making an Oral Care Visit Successful for the Client With Autism

As the dental care provider, it is important to:

- Schedule the visit for a time when the clinic is least busy. Some clinicians have even opted to open their practice on Saturday to create the quietest environment possible. Others schedule just before, or just after, regularly occurring office hours.
- Minimize wait time. Families often appreciate a heads-up if appointments are running behind.
- Use consistency in scheduling (same staff, same room, same chair). Consistency is especially important in the initial phase of visits.
- Use consistency in approach to exam – same sequence of events, familiar language/ instructional approach.
- Make manipulatives available in waiting area and in exam space.
- Ask family if child has a sensitivity to certain types of lighting. May need to modify during visit, if an issue.
- Make pictures of office building, exam space and chair, orthodontist/dentist, hygienist, available to family. Laminating will improve durability. Take a picture of a child happily undergoing an exam and make available to family for use in picture schedule.
- Make icons of tools used and create a sequence sheet. Creating a velcro sheet will allow sequence to be re-used and individualized for patients.
- Schedule a series of brief visits for newly entering patients. Pre-determine goals for each visit, in consultation with family. Keep visits successful. Avoid "going the extra mile" and squeezing in extra steps.
- Schedule a series of brief visits before a specific procedure to familiarize patient with expected experiences (and staff if it is a new patient).

Partner with families to create a successful experience

Consult with the family during an initial visit without the child present, or over the phone if that is more convenient for the family. Often unstructured time, especially during adult conversation, poses a significant challenge to the child, and therefore to the parent.

Topics for discussion

- Is a system of positive reinforcement used in child's learning process? If so, what are the preferred reinforcers? If reinforcers are to be used, determine who will provide. Often the parent is quite willing to do this, if they are familiar with this type of approach.
- How is oral care performed at home? How much prompting is required? What is child's level of tolerance and/or participation in oral hygiene? Is toothpaste used? Is mouthwash used?
- What techniques does the family employ to increase successfulness in learning new skills? What are their suggestions for employing those techniques in a clinical setting?
- Encourage caregivers/families to practice anticipated pieces of the exam at home. Provide them with tools such as popsicle sticks, bitewings, and the mouth mirror, for practicing. Once the child can tolerate the experience in a sitting position, suggest progressing to practicing with child in a supine position – if they own a recliner, so much the better.
- Emphasize importance of making practice sessions successful. Keeping them brief, progressing slowly, and offering immediate reinforcement are strategies for improving outcomes.

Troubleshooting for problems

Questions for families and caregivers to help increase sensitivity to subtle changes in child's behavior that may be indicative of a dental issue–especially important for the child with minimal or no verbal communication ability:

- Has there been a change in the child's eating habits? For instance, does he or she prefer soft foods over the usually preferred crunchy or hard items?
- Has the child been avoiding chewing on one side of the mouth or the other?
- Is drooling present or increased?
- Does the child grimace while eating, or stop eating frequently during meals?
- Does he or she chew on nonfood items? Does there seem to be an increase in this? Are the items rubbery in texture?

Making the visit a positive experience for the child is arguably the most important task to accomplish. Avoid the urge to "just get this one more thing done", or to push ahead when the child begins to show signs of frustration and anxiety. Frequently, not only does the desired task not get accomplished, but the child is even less willing to repeat any aspect of a future visit. In the event a visit is perceived as a rather negative experience, schedule another visit, or series of visits, for the purpose of regaining the child's trust. Make the goal whatever task can be successfully accomplished (even if it is just sitting in the chair), with lots of verbal approval and or positive reinforcement.

Much time and attention is required to successfully treat a child or adult with autism, but once the foundation is laid, it pays off in dividends. Not only can you feel confident about the care the child receives, but the visits become progressively more pleasant and productive instead of more anxiety producing for everyone.

Information provided by the Northwest Autism Center, 127 W. Boone Avenue, Spokane, WA 99201; 1-509-328-1582; www.nwautism.org

Appendix 14: Frequently Used Terminology

Adaptive Physical Education (APE)
A specially designed physical education program for a child with developmental disabilities. Traditional exercise forms, assessment techniques, and training protocols are adapted to meet the specific needs of a person with developmental delays or disabilities.

Adult Services
Refers to the many agencies and programs that are provided to adults with specific needs such as disability, health, and income.

Americans with Disabilities Act (ADA)
An equal opportunity, civil rights law to protect any person who has an impairment that substantially limits major life activities.

American Sign Language (ASL)
A method of communicating by using hand signs. Each sign represents either one word or concept that is typically expressed with several spoken words. For words that do not have a sign, finger-spelling is used. (Coleman, l993)

Antecedent Behavior
What happens in or to the environment right before a behavior occurs. This includes verbal, gestural or physical prompts, cues, materials, language, and environmental factors (sensory input: noise, light, smell, taste, touch), either naturally occurring or intentionally manipulated to affect a behavior.

Applied Behavior Analysis (ABA)
The science in which procedures derived from the principles of behavior are systematically applied to improve socially significant behavior to a meaningful degree and to demonstrate experimentally that the procedures employed were responsible for the improvement in behavior. (Cooper, Heron & Heward, 1987)

Asperger Disorder
One of the five Autistic Spectrum Disorders; "similar in most areas to Autism Disorder, except: no clinically significant delay in language; no clinically significant delay in cognitive development, self-help skills, adaptive skills, and curiosity about environment" (from the DSM-IV criteria).

Attention Deficit Disorder (ADD)
A term previously used to describe an individual with significant attention problems and minimal hyperactivity. This term is now represented by Attention Deficit Hyperactivity Disorder (ADHD)-inattentive type.

Attention Deficit Hyperactivity Disorder (ADHD)
The core components are a short attention span for mental age, impulsivity (acting without consideration of consequences), distractibility (inability to maintain focus due to irrelevant external or internal stimuli) and motor overactivity that ranges from fidgetiness to continuous movement. Although all children with this disorder have difficulty with attention span, not all have significant hyperactivity. Therefore, these features have been categorized into a combined type (both inattention and hyperactivity-impulsivity), an inattention type and a hyperactivity-impulsivity type. ADHD must be differentiated from other disorders that affect attention, such as anxiety disorders, depression, learning disabilities and seizures.

Auditory Integration Training (AIT)
A technique used to attempt to desensitize children with autism spectrum disorder (ASD)/pervasive developmental disorder (PDD) to certain frequencies of sound(s) that they show sensitivity. (Rimland & Edelson, l995)

Autism
As defined in the Diagnostic and Statistical Manual of Mental Disorders (DSM IV, 2000):

I. A total of six (or more) items from (A), (B), and (C), with at least two from (A), and one each from (B) and (C)

   A. Qualitative impairment in social interaction, as manifested by at least two of the following:

      1. Marked impairments in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body posture, and gestures to regulate social interaction.

      2. Failure to develop peer relationships appropriate to developmental level.

      3. A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people, (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people).

      4. A lack of social or emotional reciprocity (note: in the description, it gives the following as examples: not actively participating in simple social play or games, preferring solitary activities, or involving others in activities only as tools or "mechanical" aids).

   B. Qualitative impairments in communication as manifested by at least one of the following:

      1. Delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime).

      2. In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others.

      3. Stereotyped and repetitive use of language or idiosyncratic language

      4. Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level.

   C. Restricted repetitive and stereotyped patterns of behavior, interests and activities, as manifested by at least two of the following:

      1. Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus.

      2. Apparently inflexible adherence to specific, nonfunctional routines or rituals.

      3. Stereotyped and repetitive motor mannerisms (e.g hand or finger flapping or twisting, or complex whole-body movements) 4. persistent preoccupation with parts of objects.

II. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years:

A. Social interaction

B. Language as used in social communication

C. Symbolic or imaginative play

III. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder

Autism Behavior Checklist (ABC)
One of five independent subtests of the Autism Screening Instrument for Educational Planning.

Autism Diagnostic Interview (ADI)
A semi-structured investigator-based interview(s) for the caregivers of children and adults for whom autism or pervasive developmental disorders is a possible diagnosis. Training in this instrument should be done by qualified staff.

Autism Diagnostic Observation Schedule (ADOS)
A structured observation schedule for the diagnosis of Autism Spectrum Disorder (ASD)/Pervasive Developmental Disorder (PDD). It uses a standardized group of social contexts and attempts to encourage interactions between the individual and the interviewer. While the original ADOS can only be used with higher functioning individuals, a newer instrument is available for use with younger and nonverbal individuals. Its validity depends on the expertise of the interviewer who should be trained in its use by qualified staff.

Autistic Disorder
The presence of markedly abnormal or impaired development in social interaction and communication and markedly restricted repertoire of activity and interests. Delays with onset occur prior to age three. Manifestations of the disorder very greatly depending on developmental level and chronological age of the individual.

Autism Spectrum Disorder (ASD)
ASDs include autistic disorder, pervasive developmental disorder - not otherwise specified (PDD-NOS, including atypical autism), and Asperger syndrome. These conditions all have some of the same symptoms, but they differ in terms of when the symptoms start, how severe they are, and the exact nature of the symptoms. The three conditions, along with Rett's syndrome and childhood disintegrative disorder, make up the broad diagnosis category of pervasive developmental disorders.

Backward Planning
A step-wise planning process that starts with desired goals and plans backward to the current level of functioning and support.

Coequal
Equal with one another, as in rank or size; of equal importance.

Comorbid/Co-existing/Co-occurring
Existing simultaneously with and usually independently (though not necessarily) of another medical condition.

Developmental Disability (DD)
Under Washington State RCW 71A.10.020(3) the definition in law of a developmental disability is a disability attributable to:

- Mental Retardation
- Cerebral Palsy
- Epilepsy
- Autism

OR

- Another neurological or other condition closely related to mental retardation or that requires treatment similar to that required for individuals with mental retardation.

Which:

- Originated before the individual attained age eighteen;
- Continued or can be expected to continue indefinitely, and
- Results in substantial limitations to an individual's intellectual and/or adaptive functioning.

The criteria for eligibility are further defined in the Washington Administrative Code, WAC 388-823 effective July 5, 2005 and may be reviewed at the following link **www1.dshs.wa.gov/ddd/eligible.shtml**.

Diagnostic and Statistical Manual for Mental Disorders (**DSM-IV**)
American Psychiatric Association, 2000 (see Appendices for Diagnostic Criteria for Autistic Disorder); a classification system used by mental health professional to classify mental disorders.

Discrete Trial Training (DTT)
A training regimen in which a discrete trial is the basic teaching unit. In general, a discrete trail consists of a single instructional exchange between the instructor and the child which includes a verbal directive (e.g., "say da"), a child's response, (e.g., "da") and the instructor's feedback to the child (e.g., "Good"). DTT most often involves drills consisting of several reinforced trials. It is utilized to teach a variety of skills.

Due Process
Legal safeguards to which a person is entitled in order to protect his or her rights.

Early Intervention (EI)
Specialized services provided to infants and toddlers who are at-risk for or are showing signs of developmental delay.

Echolalia
The repetition of words. Immediate echolalia causes the immediate repetition of a word or phrase. In some autistic and Asperger's cases it may be a method of buying time to help process language. If a child with autism is asked, "Do you want dinner?" the child echoes back "Do you want dinner?" followed by a pause and then a response, "Yes. What's for dinner?" In delayed echolalia, a phrase is repeated after a delay, such as a person with autism who repeats TV commercials, favorite movie scripts, or parental reprimands.

Employment Networks (EN)
An employment network of providers participating in the Social Security Administration's Ticket to Work Program. The EN provides or coordinates employment, vocational rehabilitation, and support services to SSA beneficiaries using their tickets to work. In return, SSA pays the EN for employment outcomes achieved by the beneficiaries assigning their tickets to the EN.

Employment Specialist/Professional
Refers to and individuals that assist people with disabilities to find and keep a job. This includes job marketing/development; individual planning or discovery of an individual's interests, skills and challenges; job coaching or teaching the skills necessary to do the job; and maintenance or follow along support to help the person retain the job.

Enclave
A form of supportive employment where a group of no more than eight persons with disabilities work in an integrated employment setting often with professional supervision.

Epidemiology
The study of factors affecting the health and illness of populations, and serves as the foundation and logic of interventions made in the interest of public health and preventive medicine.

Free and Appropriate Public Education (FAPE)
Special education and related services that:

l) Have been provided at public expense, under public supervision and direction, and without charge;
2) Meet the standards of the State educational agency;
3) Include appropriate preschool, elementary, or secondary school education in the State involved;
4) Are provided in conformity with the individualized education program required by PL 105-l7, Section 614(d).

Follow-Along-Services
In Supported Employment, this term refers to services and supports provided to a worker with a disability after job training is completed.

Functional Behavior Assessment
Provides hypotheses about the relationships between specific environmental events and behaviors; the function of a behavior can be thought of as the purpose a behavior serves for a person.

Impairment Related Work Expense
Expenses related to the items a person with a disability needs because of his/her impairment in order to work; may be deducted during the eligibility process for SSDI or SSI.

Individual Earned Income Exclusion
Income that can be excluded for a individual under age 22 in calculating SSI benefits.

Individualized Education Program (IEP)
A written statement for each child with a disability that is developed and reviewed in accordance with PL l05-l7 (see appendices).

Individuals with Disabilities Education Act (IDEA)
The federal law that mandates public education for children who have disabilities.

Individualized Family Service Plan (IFSP)
A written plan providing early intervention services to an eligible child birth through two years of age and his or her family.

Incidental Teaching
A teaching method in which child-directed, natural occurring activities are used to provide instruction to the child.

Inclusion
The practice of providing a child with disabilities an education within the general education program with non-disabled peers. Supports and accommodations may be needed to assure educational success in this environment.

Job Analysis
The process of analyzing a job in terms of essential elements, skills needed, and characteristics to aid in job matching and training.

Job Carving
A technique in advanced supportive employment programs where a job is divided into components that can be done by a person with a severe disability (taking a single task away from multiple "doers" and giving it to a single doer).

Job Shadowing
The practice of allowing an individual to observe a real work setting to determine their interest and to acquaint them with the requirements of the job.

Least Restrictive Environment (LRE)
The educational setting that permits a child with disabilities to derive the most educational benefit while participating in a regular educational environment to the maximum extent possible. (Coleman, l993)

Local Education Agency (LEA)
A public board of education or other public authority legally constituted within a state of either administrative control or direction of, or to perform a service function for, public elementary or secondary schools in a city, county, township, school district, or other political subdivision.

Mental Retardation (MR)
A condition characterized by limitations in performance that result from significant impairments in measured intelligence and adaptive behavior.

Milieu Teaching
Planned teaching environment in which everyday events and interactions are therapeutically designed for the purpose of enhancing social skills and building confidence.

Natural Environment (NE)
The place where events or activities usually occur for children who are typically developing.

Natural Supports: Refers to the use of person, practices, and things that naturally occur in the environment to meet the support needs of the individual.

People First: People first language is a way of describing someone which puts the person ahead of his or her medical label. Using "people first" language, for example, an individual would be described as "a person with a disability" rather than "a disabled person" or "the disabled".

Pervasive Developmental Disorder (PDD)
A group of conditions with a common dysfunction in the domains of socialization and communication. This category includes:

- Autistic Disorder
- Asperger Syndrome
- Pervasive Developmental Disorder-Not Otherwise Specified
- Rett's Syndrome
- Childhood Disintegrative Disorder

The "classic" form of PDD is autistic disorder. The core components are qualitative impairments in socialization, communication and imaginative play and repetitive behaviors/restricted interests with onset by age 3 years.

Plan for Achieving Self Support (PASS)
A savings account that can be excluded from income and assets of persons with disabilities to allow them to save up for something that would make them self sufficient (e.g., college fund). A person who is eligible for Social Security Insurance (SSI) gets a chance at PASS.

Procedural Safeguards
Legal protections (including mechanisms or procedures) available to children, their parents and their advocates to protect their rights in dealing with agencies and providers of early intervention services.

School to Work Programs
These programs refer to general education secondary programs developed under the School-to-Work Opportunity Act of 1994 which include career education, work-based instruction experiences, and efforts to connect individuals with vocational and post-school programs.

Self-Advocacy
People with disabilities speaking up for themselves are considered self-advocates. It means that a person with a disability is entitled to be in control of their own life, their belongings and how they are used. It is about having the right to make decisions about their own life without being controlled by others.

Self-Contained Classroom
The special class/learning center shall serve children whose handicapping conditions are so severe that it requires removal from a regular education program to provide part-time or full-time educational services in this program option. Not all children assigned to a special class/learning center will necessarily remain with the special education teacher on a full-time basis. Special class/learning center program option shall include placement in a special class/learning center program located in a public school building; separate school in the school district; public school program located in a separate facility; county board of mental retardation and developmental disabilities facility; state residential school for the deaf or for the blind; or a state institution.

Sensory Integration (SI)
Therapy that is directed toward improving how an individual's senses process stimulation and work together to respond appropriately.

Sensory Motor Processing
The process by which a person takes in information from environment (through sensory receptors), interprets/integrates the information to form some meaningful concept (not necessarily conscious thought), and then uses that sensory information in a meaningful way through a motor output (action).

Social Security Disability Income (SSDI)
An income support payment administered by the Social Security Administration that is provided to wage earners who are no longer able to work because of their disability or to the unmarried adult child of a wage earner who is disabled, retired, or deceased.

Special Education
Specialized instruction designed for the unique learning strengths and needs of the individual with disabilities, from age 3 through 22.

Substantial Gainful Employment (SGA)
The amount of income a person can make after a trial work period and still receive SSI payments.

Supplemental Security Income (SSI)
An income support payment administered by the Social Security Administration that is provided to children with disabilities and adults who are disabled and whose income and assets fall below a prescribed level after accounting for social security work incentives.

Supported Employment
A form of employment where training is done at the job site and ongoing supports are provided to maintain employment. Supported Employment is meant for persons with the most severe disabilities. Supported Employment jobs are in integrated settings and may consist of individual placement, mobile work crews, or enclaves.

Transition (early intervention)
Young children who are developmentally delayed and in Part C programs for Early Intervention move from one program to the next.

Transition (adolescence)
The process of moving from adolescent to adult roles where the child reconciles their needs, interests, and preferences with adult norms and roles.

Transition Planning
An plan that focuses on individual skills, interests, and support needs in the areas of employment, future education, daily living, leisure activity, community participation, health, self-determination, communication, interpersonal relationships.

Transition from School to Work
A process of preparing a person with ASD/PDD, beginning at an early age (approximately six years of age) for a successful temporal passage of full integration into the community in terms of work, recreation, and residence.

Waiver
An exception to a rule or regulation.

Work Incentives
A number of Social Security Work Incentives that allow a person to exclude a part of their income to maintain eligibility for SSI or SSDI. Includes PASS, IRWEs, Individual Earned Income Exclusion, and extended eligibility for Medicaid.

Work Study
Jobs developed by the high school where the individual receives credit.

Appendix 15: References and Resources

Assistive Technology

Project Team: Technology to Educate Students with Autism, Johns Hopkins University - Center for Technology in Education, 6740 Alexander Bell Drive, Suite 302, Columbia, MD 21046 , (410) 312-3800, Fax (410) 312-3868

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Circles I, II, and III. Intimacy and Relationships, (teaches appropriate social distance skills) Stop Abuse, (an abuse prevention curriculum) and Safer Ways (HIV/AIDS prevention education). Leslie Walker-Hirsch, M.Ed. and Marklyn Champagne, R.N., M.S.W.

Life Horizons I and II, Sexuality Education for Persons with Severe Developmental Disabilities, Life Facts - Sexuality and Sex Abuse Prevention. These curriculums are available from:
James Stanfield Co. Inc.
Drawer 189, PO Box 41058, Santa Barbara, CA 93140
(800) 421-6534 Fax: (805) 897-1187

YAI's Relationship Series: Friendship Series, Boyfriend/Girlfriend Series, and Sexuality Series
YAI/National Institute for People with Disabilities
Tapes and Publications
460 West 34th Street, New York, NY 10001-2382
(212) 273-6517 Fax: (212) 629-4113

Sensory Integration

Anderson, E., Emmons, P. (1996). *Unlocking the Mysteries of Sensory Dysfunction: A Resource for Anyone Who Works With or Lives With, a Child With Sensory Issues*. Arlington, TX: Future Horizons

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Sexuality

There are many useful resources for providing sexuality training to children and adults with developmental disabilities including books and videotapes. Most of the tools are useful as clear and sometimes graphic descriptions of sexual functions and norms. John Mortlock reported that "Advocates of the sexual 'rights' of people with autism will not be offering positive help unless they accept the difficulty that people with autism have in making and sustaining the social interaction that is necessary in our society to establish a sexual relationship.

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Social

Attwood, Tony. (1997). *Asperger's Syndrome - A Guide for Parents and Professionals*. Philadelphia, PA: Jessica Kingsley Publishers

Baron-Cohen, P., Howlin, S. (1998). *Teaching Children with Autism to Mind-Read: A Practical Guide for Teachers and Parents*. New York, NY: John Wiley & Son Ltd.

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Duke, M., Nowicki, S.,Martin, E. (1998). *Teaching Your Child the Language of Social Success*. Atlanta, GA: Peachtree Publishers, Ltd.

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Gray, C. (1994). *The New Social Story Book*. Arlington, TX: Future Horizons Publishers.

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Maurice, C., Green, G., Luce, S.C. (1996). *Behavioral intervention for young children with autism: A Manual for Parents and Professionals*. Austin, TX: Pro.-Ed.

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Appendix 16:
Get Connected - Internet/Phone

Please be advised that this is not a comprehensive list of internet resources and is provided as a general guideline for the types of internet resources available.

Aspergers Syndrome

Asperger Syndrome Education Network, Inc. (ASPEN), www.aspennj.org

Asperger Syndrome Information and Support (OASIS), www.udel.edu/bkirby/asperger

Global and Regional Asperger Partnership (GRASP), www.grasp.org

MAAP Services (More Advanced Individuals with Autism, Asperger Syndrome, and Pervasive Developmental Disorder), www.maapservices.org

National Dissemination Center for Children with Disabilities (NICHCY) www.nichcy.org/Documents/connections/asperger.aspx

New Horizons for Learning, www.newhorizons.org/spneeds/autism/may.htm

Stephen Shore, www.autismasperger.net

Autism Diagnostics

American Academy of Pediatricians Referral Service, (847) 434-4000, www.aap.org/referral/

Children's Hospital at Legacy Emmanuel, (503) 413-2200, www.legacyhealth.org/body.cfm?id=89

Children's Village, (509) 574-3200 or 1-800-745-1077, www.yakimachildrensvillage.org (Yakima)

Mary Bridge Pediatric Neurosciences Center, (253) 403-4437, www.multicare.org/marybridge/pediatric-neurosciences-center/ (Tacoma)

Seattle Children's Autism Center, (206) 987-8080, www.seattlechildrens.org

Seattle Children's Neurodevelopmental Centers, (206) 987-2210, www.seattlechildrens.org/clinics-programs/neurodevelopmental/

UW Autism Centers, http://depts.washington.edu/uwautism

Seattle: (206)-221-6806 Tacoma: (253) 692-4721

Autism Organizations

Asperger Syndrome Coalition of the US, www.asperger.org

Autism/ADD Resources, Inc., (206) 463-5237, www.aitresources.com

Autism National Committee, www.autcom.org

Autism Network International, www.ani.ac

Autism Outreach Project, 1-888-704-9633, www.esd189.org/autism

Autism Society of Washington, 1-888-ASW 4 YOU, www.autismsocietyofwa.org

Autism Organizations (continued)

Autism Society of America, 1-800-3-Autism, www.autism-society.org

Autism Speaks National, www.autismspeaks.org

Autism Speaks Washington State e-mail: WASHINGTONSTATEADVOCACY@autismspeaks.org

C.A.P.A. (Community Alternatives for People with Autism) Tacoma (253) 536-2339

Families for Early Autism Treatment (FEAT), (206) 763-3373, www.feat.org

First Signs, www.firstsigns.org

More Advanced Individuals with Autism, Asperger, www.maapservices.org

OASIS – (Online Asperger Syndrome Information and Support), www.udel.edu/bkirby/asperger

Autism Research

Autism Collaboration, www.autism.org

Autism Research Institute, www.autism.com/ari

Autism Speaks, www.autismspeaks.org

Autism Services

Autism Community Services, (360) 735-8670 (Vancouver)

Autism Consulting Cadre-ESD 112, www.esd112.org/sss/autism/(Vancouver)

Boyer Children's Clinic, (206) 325-8477, www.boyercc.org

Children's Village, (509) 574-3200 or 1-800-745-1077, www.yakimachildrensvillage.org (Yakima)

Legacy Children's Center, (360) 695-1281 x34505, www.legacyhealth.org/body.cfm?id=1272

Haring Care Clinic, www.haringcenter.washington.edu/careclinic

Mary Bridge Pediatric Neurosciences Center, (253) 403-4437, www.multicare.org/marybridge/pediatric-neurosciences-center/ (Tacoma)

Northwest Autism Center (Spokane), (509)-328-1582, www.nwautism.org/

Providence-Sacred Heart Children's Hospital, (509) 474-2730, www.shmcchildren.org (Spokane)

Seattle Children's Autism Center, (206) 987-8080, www.seattlechildrens.org

UW Autism Centers, http://depts.washington.edu/uwautism

Seattle: (206)-221-6806 Tacoma: (253) 692-4721

Books / Videos

Autism Asperger Publishing Company, www.asperger.net/bookstore.htm

Autism Resources, www.autism-resources.com/books.html

Autism Society of America Bookstore, www.autism-society.org/

Autism Society of America - Michigan, www.autism-mi.org

Autism Society of America - North Carolina, http://secure.appcomm.net/Merchant2/merchant.mv?Store_Code=asnc

Autism Speaks Video Glossary, www.autismspeaks.org/video/glossary.php

Autism Web - A Parent's Guide to Autism and PDD, www.autismweb.com/books.htm

Future Horizons, www.futurehorizons-autism.com

Jessica Kingsley Publishers, www.jkp.com

Stanfield Publishing, Specialists in Special Education, www.stanfield.com

Taconic Resources for Independence, Inc., www.taconicresources.net

Education

American Speech-Language-Hearing Association, www.asha.org
Association for Behavior Analysis International, www.abainternational.org
Alert Program, www.alertprogram.com
Autism Consulting Cadre-ESD 112, www.esd112.org/sss/autism/(Vancouver)
Autism Outreach Project, (888) 704-9633, www.esd189.org/autism/
Autism Training for Law Enforcement, (772) 398-9756, www.policeandautism.cjb.net
Center for Disease Control and Prevention (CDC): Learn the Signs. Act Early.
www.cdc.gov/ncbddd/autism/actearly/
Center of Social and Emotional Foundations for Early Learning, www.vanderbilt.edu/csefel/contact.html
Clinical Behavior Analysts, LLC, www.abatherapy.net
DIR Floortime, www.floortime.org
DoToLearn, www.doToLearn.com
ERIC (Educational Resources Information Center), 1-800-328-027, www.ericec.org
Family Educator Partnership Project (FEPP), 1-888-754-8798
Lovaas Institute for Early Intervention, www.lovass.com
National Education Early Childhood Technical Assistance Center, www.nectac.org
NICHCY Resources, www.nichcy.org
Ohio Speech Language Hearing Association, www.oslha.org
Picture Exchange Communication System (PECS), www.pecs-usa.com
SCERTS Model-Barry Prizant, www.barryprizant.com
Social Learning and Understanding - Linda Gray, www.thegraycenter.org
Social Thinking-Michelle Winner Garcia, www.socialthinking.com
TEACCH, www.teacch.com
Visual Strategies-Linda Hodgdon, www.usevisualstrategies.com
Washington Assistive Technology Act Program (WATAP), 1-800-214-8731, http://wata.org

Family Support

Arc of Washington State, 1-888-754-8798, www.arcwa.org
Families for Early Autism Treatment (FEAT), (206) 763-3373, www.feat.org
Family Health Hotline, 1-800-322-2588
Father's Network of Washington State, (425) 747-4004, www.fathersnetwork.org
Kinship Care in Washington, 1-800-737-0617, www.dshs.wa.gov/kinship
Parent to Parent, 1-800-821-5927, www.arcwa.org/parent_to_parent.htm
PAVE of Washington, 1-800-5 PARENT, www.washingtonpave.org
Self Advocates of Washington (SAW), www.jcchoices.org/orgs/383.html
STOMP (Specialized Training of Military Parents), 1-800-572-7368, www.stompproject.org
Washington State Medical Home, www.medicalhome.org/diagnoses/autism.cfm
Within Reach Family, www.withinreachwa.org

Federal Agencies

Center for Disease Control and Prevention (CDC): Autism Information Center
www.cdc.gov/ncbddd/autism/index.htm

National Academy of Sciences, www.nasonline.org

National Institute of Health, www.nih.gov

National Institute on Mental Health, www.nimh.nih.gov/publicat/autism.cfm

Office of Special Education Programs (OSEP), www.ed.gov/about/offices/list/osers/osep/index.html

United States Congress, www.congress.org

United States Department of Education, www.ed.gov

United States House of Representatives, www.house.gov

United States Senate, www.senate.gov

Higher Education

Disabilities, Opportunities, Internetworking, and Technology, www.washington.edu/doit

Disability Support Services Council in Washington State, (360) 704-4400, www.sbctc.ctc.edu/index.aspx

Education Quest Foundation, www.educationquest.org/swd.asp

Financial Aid for Students with Disabilities, (206) 685-DOIT, www.washington.edu/doit/Brochures/Academics/financial-aid.html

Thinkcollege.net, www.thinkcollege.net

Legal Assistance

Northwest Justice Project, 1-888-201-1014, www.nwjustice.org

People First of Washington 1-800-758-1123, www.peoplefirstofwashington.org

Self Advocates In Leadership (SAIL), www.sailcoalition.org

National Organizations

American Academy of Pediatricians Referral Service, www.aap.org/referral/

American Association of People with Disabilities, www.aapd.com

Arc of the United States, www.thearc.org

Children and Adults with Attention Deficit Disorder, www.chadd.org

Developmental Disabilities Council, 1-800-634-4473, www.ddc.wa.gov

Learning Disabilities Association, www.LDOnLine.org

National Info Center for Children and Youth with Disabilities (NICHCY), www.nichcy.org

National Institute for People with Disabilities, www.yai.org

National Institute of Mental Health
www.nimh.nih.gov/health/publications/autism/index.shtml

National Organization on Disabilities, www.nod.org

National Parent Network on Disabilities, www.npnd.org

Technical Assistance Alliance for Parent Centers, www.taalliance.org

The Association for Persons with Severe Handicaps (TASH), www.tash.org

Special Education Law

Client Assistance Program, www.washingtoncap.org COPAA (Council of Parent Advocates and Attorneys, www.copaa.net

Developmental Disabilities Council, www.ddc.wa.gov Disability Rights Adovates, www.dralegal.org

Disability Rights Washington (formerly WA Protection and Advocacy System), www.disabilityrightswa.org

IDEA Technical Assistance Paper - Office of Superintendent of Public Instruction (OSPI) WA www.k12.wa.us/Specialed/pubdocs/TAP1.pdf

Reed Martin, www.reedmartin.com

Special Education Ombudsman, www.k12.wa.us/SpecialEd/Ombudsman.aspx

Special Education Law Guide - Office of Superintendent of Public Instruction (OSPI) WA www.k12.wa.us/Specialed/pubdocs/special_education_law_guide.pdf

Wrightslaw, www.wrightslaw.com

Transition

Adolescent Health and Transition Project, (206) 598-6804, (206) 616-1660 http://depts.washington.edu/healthtr/

Center for Change in Transition Services, (206) 296-6494, www.seattleu.edu/ccts

Self Employment and Social Security Work Incentives for Person's with Disabilities (Consulting and Training on Employment and Transition to Work), www.griffinhammis.com

U.S. Department of Education Office of Civil Rights - Serving student populations facing discrimination and the advocates and institutions promoting systemic solutions to civil rights problems, (800) 872-5327, www.ed.gov/about/offices/list/ocr/index.html

Washington Initiative for Supported Employment, www.theinitiative.ws/

Washington State Agencies

Department of Early Learning (DEL):

- Early Support for Infants and Toddlers, Ages Birth through 2, 1-800-322-2588 http://del.wa.gov/development/esit/Default.aspx

Department of Health (DOH):

- Adolescent Health and Transition Project, (206) 598-6804, (206) 616-1660 http://depts.washington.edu/healthtr/
- Autism Awareness Project, www.doh.wa.gov/cfh/mch/Autism/Autism.htm
- Children with Special Health Care Needs, (360) 236-3571, www.doh.wa.gov/cfh/mch/CSHCNhome2.htm
- Medical Home Leadership Network, www.medicalhome.org/leadership/the_mhln.cfm
- Washington State Medical Home - Autism, www.medicalhome.org/diagnoses/autism.cfm

Department of Social and Health Services (DSHS):

- Division of Developmental Disabilities (DDD), www.dshs.wa.gov/ddd
- Division of Mental Health- Regional Support Networks Services Information (RSN) www.dshs.wa.gov/mentalhealth/rsnmap.shtml
- Division of Vocational Rehabilitation, www1.dshs.wa.gov/dvrState Children's Health Insurance Program (SCHIP), 1-877-KIDS-NOW, 1-877-543-7669) http://hrsa.dshs.wa.gov/CHIP/Index.html

Washington State Agencies (continued)

Office of the Education Ombudsman, (206) 729-3232, www.governor.wa.gov/oeo/about.asp

Office of Superintendent of Public Instruction (OSPI):

- Autism Outreach Project, 1-888-704-9633, www.esd189.org/autism
- Career and Technical Education, www.k12.wa.us/careerteched/
- Programs for Children with Disabilities: Ages 3 through 5, www.k12.wa.us/SpecialEd/EC.aspx
- Regional ADA Technical Assistance Center, www.dbtacnorthwest.org
- Special Education, www.k12.wa.us/specialed
- State Coordinator for NCLB (No Child Left Behind), www.k12.wa.us/ESEA/default.aspx

University of Washington:

- Adolescent Health and Transition Project, (206) 598-6804, (206) 616-1660
  http://depts.washington.edu/healthtr/
- Adults and Elders, (206) 616-1660
  http://depts.washington.edu/chdd/ucedd/adults_eld_1/1_aemain.html
- Autism Centers, http://depts.washington.edu/uwautism
  Seattle: (206)-221-6806 Tacoma: (253) 692-4721
- Center for Technology and Disability Studies, (206)685-4181
  http://depts.washington.edu/chdd/ucedd/ctds_4/4_ctdsmain.html
- Center on Human Development and Disability (CHDD), www.chdd.washington.edu
- Center on Infant and Mental Health Development, (206) 543-8453
  http://depts.washington.edu/chdd/ucedd/cimhd_3/3_cimhdmain.html
- Community Disability Policy Initiative, (206) 685-4010
  http://depts.washington.edu/chdd/ucedd/cdpi_6/6_cdpimain.html
- Haring Care Clinic, www.haringcenter.washington.edu/careclinic
- Experimental Education Unit, (206) 616-3450
  http://depts.washington.edu/chdd/ucedd/eeu_7/7_eeumain.html
- Genetics Unit, (206) 543-3370, (206) 277-1825
  http://depts.washington.edu/chdd/ucedd/genetic_8/8_geneticsmain.html
- LEND Clinical Training Unit, (206) 685-1350
  http://depts.washington.edu/lend/
- University Center for Excellence in Developmental Disabilities, (206) 543-7701

Washington State Autism Lifespan Resource Tree

Washington statewide services and supports for individuals with suspected or known autism spectrum disorders (ASD). Detailed contact information is provided in the following Autism Lifespan Resource Directory.

Early Identification, Screening, Diagnosis and Evaluation

Call your child's pediatrician or family physician for screening or referral.

To find a Washington pediatrician, contact:

American Academy of Pediatricians Referral Service
(847) 434-4000

For multi-disciplinary evaluation:

Mary Bridge Children's Hospital in Tacoma
(800) 552-1419

Seattle Children's Autism Center
(206) 987-8080

Seattle Children's Neurodevelopmental Centers
(206) 987-2210

University of Washington Center on Human Development and Disability
(206) 685-1356

Early Support for Infants and Toddlers Birth to 3
1-800-322-2588

Contact to find the office serving your region by phone, e-mail or Internet.

For additional state/regional information and referrals, contact:

Autism Society of Washington
(888) 279-4968

Children's Village in Yakima
(800) 745-1077

Northwest Autism Center in Spokane
(509) 328-1582

Washington State Medical Home
(206) 685-1279

Early Interventions, Treatment, Therapies, Home Programs

For information regarding home intervention programs for your child, contact:

Families for Effective Autism Treatment (FEAT)
(206) 763-3373

For specialized therapies:

Neurodevelopmental Centers
1-800-322-2588

Primary centers of service/consultation:

Children's Village in Yakima
(800) 745-1077

Mary Bridge Children's Hospital in Tacoma
(800) 552-1419

Seattle Children's Autism Center
(206) 987-8080

University of Washington Autism Center:

Seattle Clinic
(206) 221-6806

Tacoma Clinic
(253) 692-4721

Autism Education and Training

Education for educators, parents and caregivers:

Autism Outreach Project
(888) 704-9633

PAVE of Washington
(800) 572-7368

For speakers, workshops and conferences:

Arc of Washington
(888) 754-8798

Autism Society of Washington
(888) 279-4968

Northwest Autism Center in Spokane
(509) 328-1582

The PDA Center: Professional Development in Autism
(206) 221-4202

ESD 112 Regional Autism Consulting Cadre
(360) 750-7500

Paid Services, State Insurance Coverage, and Other Financial Supports

For state funded services and supports, including respite and personal care, food stamps, temporary aid, and childcare subsidies, apply to:

DSHS-Division of Developmental Disabilities
(360) 725-3413

To find medical programs for your child or your family, contact:

DSHS Medical Programs

For disability benefits or SSI:

Social Security
(800) 772-1213

For insurance needs:

WA Basic Health
(800) 660-9840

SHIBA Hotline
(800) 562-6900

Autism and Public Education: Your Child's Primary Service Provider Ages 3 - 21

Superintendent of Public Instruction (OSPI)
(360) 725-6075

Autism Outreach Project
(888) 704-9633

For public school programs for children ages 3-5, contact:
OSPI: Programs for Children with Disabilities
(360) 753-0317

Office of the Education Ombudsman
(866) 297-2597

The PDA Center: Professional Development in Autism
(206) 221-4202

To help solve disputes with school districts:
Sound Options Special Education Mediation
(800) 692-2540

Families for Effective Autism Treatment (FEAT)
(206) 763-3373

Special Education Ombudsman
(360) 725-6075

For assistance and advocacy in accessing services:
PAVE of Washington
(800) 572-7368

Transition to Higher Education & Employment

Secondary education and career preparation:
OSPI
(360) 753-2062

Post-secondary education preparation:
US Dept. of Education Office of Civil Rights
(800) 872-5327

DSHS-Division of Vocational Rehabilitation
(800) 637-5627

Online Career Site
UW DO-IT
(888) 972-3648

Wasington Initiative for Supported Employment
(206) 343-0881

Advocacy, Legal Support, Disability and Special Education Law for Children and Adults

To join self-advocacy groups, contact:
Self Advocates of Washington (SAW)
(253) 565-3091
Self Advocates in Leadership (SAIL)
(888) 754-8798
People First of Washington
(800) 758-1123

Washington State Autism Speaks

Developmental Disabilities Council
(800) 634-4473
Arc of WA State
(888) 754-8798

Disability Rights of Washington
(206) 324-1521

Washington State Client Assistance Program
(800) 544-2121

DSHS-Legal Planning
(800) 737-0617

Washington Attorney Referral Service
and
Northwest Justice Project
(888) 201-1014

Medical and Mental Health Services

DSHS-Mental Health Division
(800) 446-0259
and
Regional Support Networks

DSHS-Division of Developmental Disabilities
(360) 725-3413

DSHS-Medicaid Benefits
and
Medicaid Mental Health
(888) 713-6010

National Alliance on Mental Illness (NAMI) of WA
(800) 782-0957

Washington State Medical Home
(206) 685-1279

Individual & Family Supports, Cultural Supports, Community Supports

Kinship Care of WA
1-800-737-0617

For summer camps and programs:
Center for Children with Special Needs
(206) 987-2000
Easter Seals
(206) 281-5700

Arc of Washington
(888) 754-8798
Autism Society of Washington
(888) 279-4968
Fathers Network
(425) 653-4286
Parent to Parent
(800) 821-5927

NW Autism Center
(509) 328-1582

For public health nursing and care coordination within local health departments:
CSHCN Coordinators
1-800-322-2588

DSHS-Division of Developmental Disabilities
(360) 725-3413

Housing, Assisted Living, and Assistive Technology

DSHS-Aging and Disability Services Administration
(800) 737-0617

Housing and Urban Development:
HUD of Washington
(800) 225-5342

Supported living opportunities for adults:
Division of Developmental Disabilities Residential Services
(360) 725-3413

Financial Aid for Students with Disabilities
(206) 685-DOIT

Easter Seals
(206) 281-5700
WA Assistive Technology Act Program (WATAP)
(800) 214-8731
WA Assistive Technology Foundation (WATF) Access Fund
(800) 214-8731

Washington State Autism Lifespan Resource Directory

The following is a convenient public reference to accessible services and supports in Washington state for children with autism spectrum disorder and their families. Neither the Caring for Washington Individuals With Autism Task Force nor the Department of Health assumes any legal liability or responsibility for the accuracy, completeness, or usefulness of any information, product, or process disclosed within.

American Academy of Pediatricians
Referral Service - locate an AAP member in your area:
(847) 434-4400
www.aap.org/referral/

Arc of Washington State
Advocacy and support for people with developmental disabilities and their families re: birth to three services, special education, employment, residential supports, health care, transportation, respite and inclusion.
2638 State Avenue NE
Olympia, WA 98506
(360) 357-5596
Toll free: (888) 754-8798
Fax: (360) 357-3279
E-mail: info@arcwa.org
www.arcwa.org

Autism Outreach Project
Information, referrals, and training on program development for students with autism spectrum disorders to Washington families, schools, and agencies.
Northwest ESD 189
1601 R Avenue
Anacortes WA 98221
Toll free: (888) 704-9633
E-mail: autism@esd189.org
www.esd189.org/autism/

Autism Society of Washington
Advocacy, public awareness, education and research related to autism. Local chapters throughout state.
1101 Eastside Street, Suite B
Olympia, WA 98501
Toll free: (888) 279-4968
Email: info@autismsocietyofwa.org
Listserve:listserve@autismsocietyofwa.org
www.autismsocietyofwa.org

Autism Speaks of Washington State
National autism organization with state representation.
E-mail: WashingtonStateAdvocacy@autismspeaks.org
www.autismspeaks.org

Boyer Children's Clinic
Therapy and early childhood educational facility serving children from birth to teen who have neuromuscular disorders or delay in development.
1850 Boyer Avenue East
Seattle, WA 98112
(206) 325-8477
Fax: (206)323-1385
www.boyercc.org

Center for Change in Transition Services
Improves post-school outcomes for individuals with disabilities in Washington state through resources, training and technical assistance.
Seattle University - College of Education
PO Box 222000
Seattle, WA 98122
(206) 296-6494
E-mail: ccts@seattleu.edu
www.seattleu.edu/ccts/

Center for Children with Special Needs
Find information on diagnoses, organize medical information with a Care Notebook, create a plan of care, find support through others with similar experiences, or look up community-based resources.
www.cshcn.org

Children's Village
Family support, and clinical and educational services to children with disabilities.
3801 Kern Road
Yakima, WA 98902
(509) 574-3200
Toll free: (800) 745-1077
www.yakimachildrensvillage.org

Community Alternatives for People with Autism (CAPA)
Provides tenant support services, supported employment, community access, job placement and vocational assessment to adults with autism.
12001 Pacific Avenue, #201,202
Tacoma, WA 98444
CAPA (253) 536-2339
Keystone (253) 536-6559
E-mail: CAPAAUTISM@AOL.com

Developmental Disabilities Council (DDC) for Washington State
Appointed by the Governor to promote a comprehensive system of services, and serve as an advocate and a planning body for Washington state citizens with developmental disabilities.
2600 Martin Way, Suite F
Olympia, WA 98506
(360) 586-3560
Toll free: (800) 634-4473
Fax: (360) 586-2424
www.ddc.wa.gov

Disability Rights of Washington (DRW)
Supports and pursues justice on matters related to human & legal rights for individuals with disabilities
315 5th Ave. So., Suite 850
Seattle, WA 98104
(206) 324-1521
Toll free: (800) 562-2702
TTY: (800) 905-0209
Fax: (206) 957-0729
www.disabilityrightswa.org

DO-IT (Disabilities, Opportunities, Internetworking, and Technology)
Increase the successful participation of individuals with disabilities in challenging academic programs in science, engineering, mathematics, and technology.
University of Washington
BOX 355670
Seattle, WA 98195-5670
(206) 685-3648/TTY
Toll free: (888) 972-3648
Fax: (206) 221-4171
Email: doit@u.washington.edu
www.washington.edu/doit/

Department of Social and Health Services (DSHS), Washington State
Multi-service agency providing protection, comfort, food assistance, financial aid, medical care and other services to WA children, families, and vulnerable adults.
Contact DSHS Constituent Services
PO Box 45130
Olympia, WA 98504-5130
Toll free: (800) 737-0617
www1.dshs.wa.gov

DSHS - Aging and Disability Services Administration
Serves adults with chronic illnesses or conditions and people of all ages with developmental disabilities. Go to website to find local offices.
640 Woodland Square Loop
Lacey, WA 98503
(360) 725-2300
www.aasa.dshs.wa.gov

DSHS-Division of Developmental Disabilities (DDD)
Assists WA State individuals with developmental disabilities and their families to obtain services and supports.
PO Box 45310
Olympia, WA 98504-5310
Fax: (360) 902-8482
TTY: (360) 902-8455
www.dshs.wa.gov/ddd/

DSHS-Division of Mental Health
Serves those with mental illnesses or mental health crises who are without financial resources to access care. Contact for list of regional centers.
1115 Washington Street
Olympia, WA 98504-5320
(360) 902-8070
Toll free: (800) 446-0259
www.dshs.wa.gov/mentalhealth/

DSHS-Division of Vocational Rehabilitation (DVR)
Employment-related services to individuals with disabilities who want to work but need assistance.
PO Box 45340
Olympia, WA 98504-5340
Toll free: (800) 637-5627
TTY: (360) 725-3636,
Fax: (360) 438-8007
www1.dshs.wa.gov/dvr/

DSHS: Medicaid Mental Health
Toll free: (888) 713-6010
www.dshs.wa.gov/mentalhealth/benefits.shtml

DSHS: Residential Services Under Developmental Disabilities Division
(360) 725-3413
To apply for services:
www.dshs.wa.gov/ddd/eligible.shtml
To find a local office:
www.dshs.wa.gov/ddd/contacts.shtml

Easter Seals of Washington State
Provides variety of services to ensure equal opportunities.
220 W. Mercer Street, Suite 120-W
Seattle, WA 98119
(206) 281-5700/TTY
Fax: (206) 284-0938
www.wa.easterseals.com

Educational Service District 112 - Regional Autism Consulting Cadre
Provides best practice training and education for children with autism.
2500 NE 65th Avenue
Vancouver, WA 98661
(360) 750-7500
www.esd112.org/sss/autism/

Early Support for Infants and Toddlers - Birth to Age 3 Department of Early Learning
Early intervention services for eligible children from birth to age 3 and families.
649 Woodland Square Lp SE
Lacey, WA 98503-1035
(360) 725-4665
Toll free: (866) 482-4325
http://del.wa.gov/development/esit/Default.aspx

Family to Family Health Information Center
Individual information on how to advocate for your child in the health care system and resources that are available in Washington state.
6316 So. 12th Street
Tacoma, WA 98465
(253) 565-2266
Toll free: (800) 572-7368
Fax: (253) 566-8052
www.familyvoicesofwashington.com

Fathers Network of WA State
Supports fathers and families raising children with special health care needs and developmental disabilities.
16120 N.E. Eight Street
Bellevue, WA 98008-3937
(425) 653-4286
Fax: (425) 747-1069
Email: greg.schell@kindering.org
www.fathersnetwork.org

F.E.A.T. (Families for Effective Autism Treatment) of Washington
Information, resources, training and services for research-based home intervention programs.
14434 NE 8th St, 2nd Floor
Bellevue, WA 98007
(206) 763-3373
Email: FEATwa@featwa.org
www.featwa.org

Financial Aid for Students with Disabilities
Provides information about scholarships and fellowships.
(724) 538-4500 - Washington D.C.
E-mail: faq@finaid.org
www.finaid.org/otheraid/disabled.phtml

HUD of Washington State
Housing services and information.
Seattle Federal Office Building
909 First Avenue, Suite 200
Seattle, WA 98104-1000
(206) 220-5101
Toll-free: (800) 225-5342
TTY: (206) 220-5254

Spokane Field Office
Thomas Foley U.S. Courthouse
920 West Riverside, Suite 588
Spokane, WA. 99201
(509) 368-3200
TTY: (509) 368-3220
www.hud.gov/local/index.cfm?state=wa

Legacy Children's Center
Comprehensive pediatric development and rehabilitation center providing assessment, coordination of services, and care.
2121 NE 139th Street, Bldg A, Suite 200
Vancouver, WA 98686
(360) 487-1777
Fax: (360) 487-1779
www.legacyhealth.org/body.cfm?id=1272

Mary Bridge Children's Hospital
Pediatric psychological services, diagnosis, assessments, therapies, care coordination.
1220 Division
Tacoma, WA 98415
(253) 403-4437
Fax: (253) 403-1235
www.multicare.org/marybridge/pediatric-neurosciences-center/

National Alliance on Mental Illness (NAMI)
Provides advocacy, public education, information/referral, and self-help support groups for people with mental illness and their families.
NW 70th Street
Seattle, WA 98117
Voice & TTY: (206) 783-9264
Toll free: (800) 782-0957
www.nami-greaterseattle.org

Northwest Autism Center
Information, referral and support; advocacy; education and training; early intervention preschool for children with autism spectrum disorders.
Serves Spokane and the Inland Northwest
127 West Boone
Spokane, WA 99201
(509) 328-1582
E-mail: info@nwautism.org
www.nwautism.org

Northwest Justice Project: Coordinated Legal Education, Advice & Referral (CLEAR)
Provides phone service for eligible low-income people to obtain free legal assistance with civil legal problems.
(253) 272-7879
Toll free: (888) 201-1014
www.nwjustice.org/

Office of the Education Ombudsman
Assists families and educators across the state with conflict resolution strategies.
Northgate Executive Center 1, Bldg B
155 NE 100th Street, Suite 210
Seattle, WA 98125-8012
(206) 729-3232
Toll free: (866) 297-2597
Fax: (206) 729-3251
www.governor.wa.gov/oeo/about.asp

Office of the Superintendent of Public Instruction (OSPI)
Special Education Services for preschool ages 3 to 21.
Old Capitol Building
600 Washington St. SE
Olympia, WA 98504-7200
(360) 725-6000
TTY: (360) 664-3631
E-mail: speced@k12.wa.us
www.k12.wa.us/SpecialEd/default.aspx

Parent Coalitions of Washington State
Provides information and resources to families. Find a local Parent Coalition:
http://washingtonparentcoalitions.com/default.aspx

Parent to Parent of Washington State
Emotional support and information to families of children with special needs and/or disabilities. Also offer trainings and educational events.
4738 172nd Ct. SE
Bellevue, WA 98006
Toll free: (800) 821-5927
Email: statep2p@earthlink.net
www.arcwa.org/parent_to_parent.htm

PAVE of Washington State
Parent-directed, non-profit organization providing information, training, support, referral services & education advocacy.
6316 So. 12th Street
Tacoma, WA 98465
(253) 565-2266
Toll free: (800) 572-7368
Fax: (253) 566-8052
www.washingtonpave.org

PDA Center - Professional Development in Autism
Provides training and consultation to school teams who work with students with ASD from diagnosis through age 21.
University of Washington - Experimental Education Unit
Box 357925
Seattle, Washington 98195
(206) 221-4202
http://depts.washington.edu/pdacent/index.html

People First of Washington
Supports individuals with self-advocacy information, training.
P.O. Box 648
Clarkston, Washington 99403
(800) 758-1123
E-mail: pfow@clarkston.com
www.peoplefirstofwashington.org

Providence-Sacred Heart Children's Hospital - Spokane
Evaluates and treats children with developmental disorders, like autism.
101 W. Eighth Avenue, Ste. E4200
Spokane, WA 99204
(509) 474-2730
www.shmcchildren.org

Seattle Children's Autism Center
Diagnosis, evaluation & long-term management of Autism.
4909 25th Avenue NE
Seattle, WA 98105
(206) 987-8080
Fax: (206) 987-8081
www.seattlechildrens.org

Seattle Children's Neurodevelopmental Programs
Evaluates and cares for children with conditions related to the development of the nervous system, including the brain.
4800 Sand Point Way NE
Seattle, WA 98105
(206) 987-2210
Toll free: (866) 987-2000
Fax: (206) 987-3824
www.seattlechildrens.org/clinics-programs/neurodevelopmental/

Self Advocates in Leadership (SAIL)
Supports individuals with self-advocacy information, and training throughout the state of Washington.
Toll free: (888) 754-8798
www.sailcoalition.org

SHIBA Helpline - Statewide Health Insurance Benefits Advisors
Consumer counseling and information/ referral regarding public and private health care options.
Office of the Insurance Commissioner
PO Box 40256
Olympia, WA 98504-0256
Toll free: (800) 562-6900
TTY: (360) 586-0241
www.insurance.wa.gov/shiba/index.shtml

Social Security Office - Washington
Toll free: (800) 772-1213
Toll free TDD: (800) 325-0778
www.socialsecurity.gov/seattle/

Sound Options Special Education Mediation
Communication and conflict resolution support and training to Washington residents and organizations.
PO Box 11457
Bainbridge Island, WA 98110-5457
(206) 842-2298
Toll free: (800) 692-2540
www.soundoptionsgroup.com

Special Education Ombudsman
Support to parents, guardians, educators, and students with disabilities, concerning laws, rules, and regulations.
Office of the Superintendent of Public Instruction
Old Capitol Building
600 Washington St. SE
Olympia, WA 98504-7200
(360) 725-6075
www.k12.wa.us/specialed/ombudsman.aspx

STOMP - Specialized Training of Military Parents
National Parent Training and Information Center for military families providing support and advice to military parents without regard of the type of medical condition their child has.
6316 So. 12th Street
Tacoma, WA 98465
Toll free: 1-800-5-PARENT
TTY: (253) 565-2266
Fax: (253) 566-8052
www.stompproject.org

University of Washington Autism Center
Diagnostic evaluations and multi-disciplinary intervention services for children with autism spectrum disorders from infancy through adolescence.

Seattle Clinic: 1701 Columbia Road
Seattle, WA 98195-7920
(206) 221-6806
http://depts.washington.edu/uwautism/

Tacoma Clinic: Cherry Parkes Bldg
1900 Commerce Street
Tacoma, WA 98402-8455
(253) 692-4721
http://depts.washington.edu/uwautism/Tacoma/

University of Washington CARE Clinic
Serves individuals from infancy through adulthood who have neurodevelopmental differences (including autism spectrum, ADHD, learning disability, and developmental delays) and their families.
3945 15th Avenue NE
Seattle, WA 98195
(206) 897-1603
www.haringcenter.washington.edu/careclinic

University of Washington Center on Human Development and Disability
Provides diagnosis, assessment and management plans for children from early childhood to adolescence with or at risk for neurodevelopmental disabilities.
Box 357920
Seattle, WA 98195
(206) 685-1356
http://depts.washington.edu/chdd/ucedd/ctu_5/child_devclinic_5.html

Washington Access Fund
Provides affordable credit and learning opportunities for assistive technology and small business to individuals with disabilities.
100 S King Street, Suite 280
Seattle, WA 98104
(206) 328-5116
Toll free: (877) 428-5116
TTY: (888) 808-8942
Email: info@washingtonaccessfund.org
www.washingtonaccessfund.org

Washington Assistive Technology Alliance Program (WATAP)
Provides Assistive Technology resources and expertise to all Washingtonians with disabilities to aid in making decisions and obtaining the technology and related services needed for employment, education and independent living.
University of Washington
Box 357920
Seattle, WA 98195-7920
(206) 685-4181
Toll free: (800) 214-8731
TTY: (866) 866-0162
Fax: (206) 543-4779
www.watap.org

Washington Basic Health
Reduced-cost health care coverage to qualified Washington State residents.
P.O. Box 42683
Olympia, WA 98504-2683
Toll free: (800) 660-9840
TTY: (888) 923-5622
www.basichealth.hca.wa.gov/

Washington Initiative for Supported Employment (WISE)
Educational and consulting services, training and technical assistance, accessible electronic and information technology and other disability related civil rights laws.
100 S. King St., Suite 260
Seattle, WA 98104
(206) 343-0881
www.theinitiative.ws/

Washington State Client Assistance Program
Assist with questions about vocational rehabilitation services.
2531 Rainier Avenue S
Seattle, WA 98144
Toll free: (800) 544-2121
TTY: (888) 721-6072
E-mail: info@washingtoncap.org
www.washingtoncap.org

Washington State Medical Home
Helps individuals and families to partner with health care providers, understand health conditions, and make informed health care decisions.
Box 357920-7920
Seattle, WA 98195
(206) 685-1279
E-mail: info@medicalhome.org
www.medicalhome.org

WithinReach
Connects families to food and health resources.
155 N.E. 100th St., #500
Seattle, WA 98125
(206) 284-2465
Email: info@withinreachwa.org
Fax: (206) 270-8891
www.parenthelp123.org
Family Health Hotline: 1-800-322-2588
http://withinreachwa.org

Autism Guidebook for Washington State

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