



AUTISM

Reaching for a brighter future

SERVICE GUIDELINES for
INDIVIDUALS with AUTISM SPECTRUM DISORDER/
PERVASIVE DEVELOPMENTAL DISORDER (ASD/PDD)
Birth through Twenty-One

HISTORY

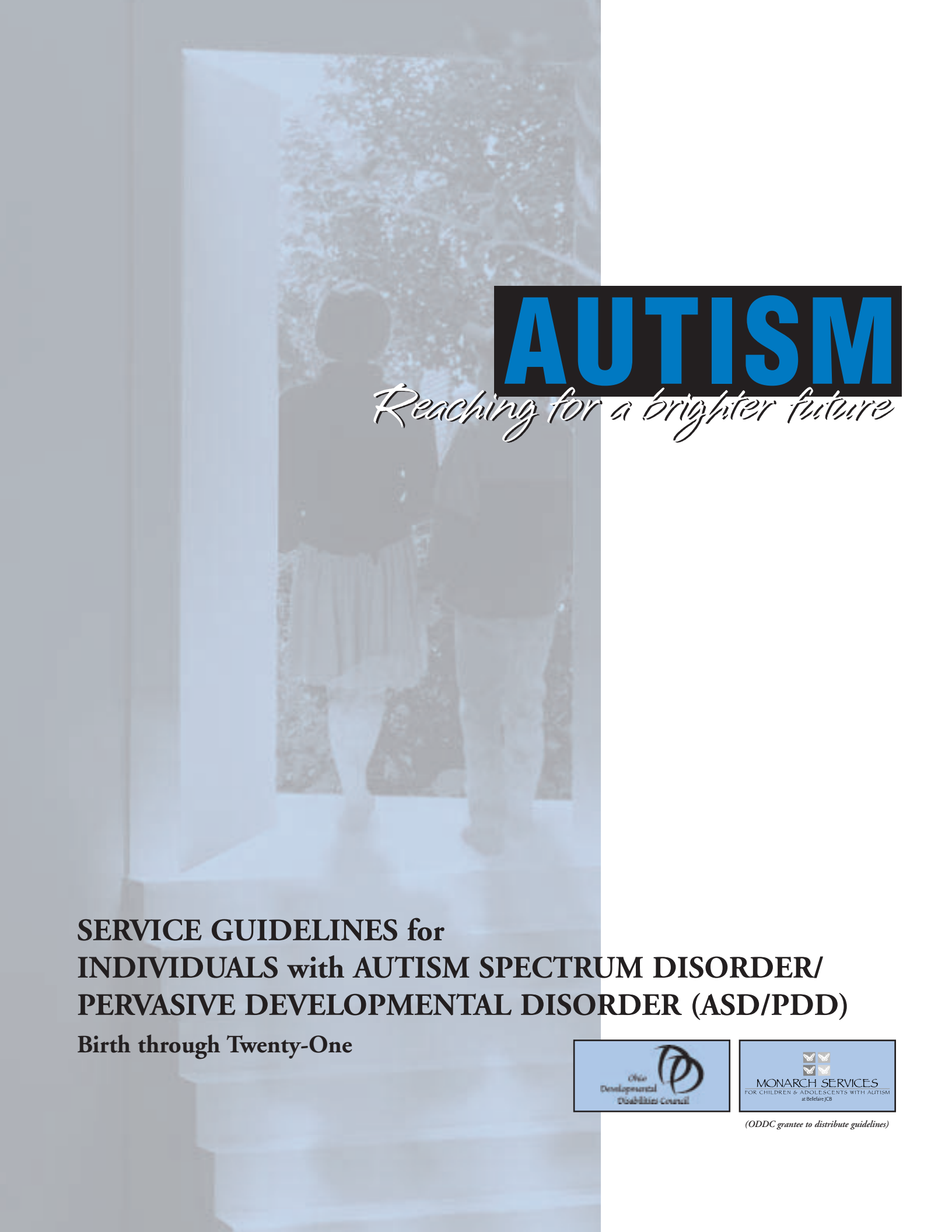
This document was developed through the efforts of the Autism Task Force, a group comprised of parents and professionals.

The purpose of the initial document was to provide guidelines in assisting families and professionals in assessing, treating, and developing educational programs for young children who exhibited characteristics of Autism Spectrum Disorder/Pervasive Developmental Disorder birth through five. There were three committees who contributed to the document, focusing on Family Support, Medical, and Education. The Autism Task Force completed the birth through five guidelines in partnership with the Bureau for Children with Medical Handicaps and the Bureau of Early Intervention Services of the Ohio Department of Health.

It was the decision of the task force members to continue their efforts by writing guidelines for individuals with ASD/PDD ages six through twenty-one. The task force membership was expanded to include expertise in the areas of adolescents and adults with ASD/PDD.

Additionally, a Community Transition committee was added. The Ohio Developmental Disabilities Council supported the effort by providing staff assistance.

The birth through five and six through twenty-one documents were merged to create the final document as presented. The Ohio Developmental Disabilities Council approved funding for a project to market and distribute the guidelines to professionals and families of individuals with ASD/PDD. Thanks are given to the members of the Autism Task Force for without their dedication and tireless efforts, these guidelines would not have been possible.



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(ODDC grantee to distribute guidelines)

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PURPOSE and SOURCE

THESE GUIDELINES OFFER BASIC CONCEPTS in providing supports for individuals with Autism Spectrum Disorder/Pervasive Developmental Disorder (ASD/PDD). The information and recommended strategies and modifications were compiled by committees and agreed upon by the “*Task Force to Develop Guidelines for Educating Individuals with ASD/PDD Ages Birth to 21.*”

The guidelines are intended to serve as a tool that can be used to help families, educators, medical professionals, care providers and other service providers make informed decisions about children and young adults with ASD/PDD. They can be viewed as a map to the development of independence for the individual with ASD/PDD 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 Ohio.

These guidelines are intended to provide recommendations based on current knowledge about “*best practices*” for the assessment of individual needs and the delivery of appropriate services and supports to children and young 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. The guidelines have a primary focus on children ages infancy to adulthood; however, this is acknowledged to be an ongoing process.

The guidelines were developed in response to the rapidly growing body of knowledge that is available regarding autism spectrum disorder. This information has expanded the opportunities available to families and professionals to improve the lives of individuals with the disorder.

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 child with autism into institutional care to spare the family the stress and heartache of attempting to raise the child. However, recent research has demonstrated that by providing the child with autism appropriate services and supports at appropriate developmental levels, significant gains in most life areas can be achieved and the person with ASD/PDD can thrive. Also, due to a shift to the “*spectrum*” view of ASD/PDD, we now 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 greatly from them. This increased rate of identification has moved the diagnostic category of ASD/PDD from being considered a low incidence disorder to a relatively high incidence disorder. This shift requires changes in attitudes, policies, and the allocation of resources to address the needs of every person with ASD/PDD in a fair and appropriate manner.

HOW TO USE THIS DOCUMENT

DESCRIPTION

The sections in this document cover a variety of information on autism:

- Definition
- Medical Aspects
- Components of Learning
- Components of Instruction and Resources

Autism is defined differently in the fields of education and medicine. A description and educational and medical definitions are provided. Education includes: Learning, Curricula and Instruction. An appendix on resources is also included for further reference and research.

It is recommended that the user of this document **not** look at the sections in isolation. Given the complex nature of ASD/PDD, delivery of educational supports often requires consideration of many aspects of the person at once. Cross-referencing is provided to assist the reader in gaining a more comprehensive understanding of each of the topics. Having the reader familiar with all contents of this document is ideal.

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. The decision to adopt a particular recommendation must be made relative to circumstances presented by an individual and his or her family.

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 the education team to develop a plan. 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/PDD in Ohio.

They are not intended to support any specific intervention, treatment program, methodology, or medication.

Introduction to Autism

WHAT IS AUTISM OR AUTISM SPECTRUM DISORDER?

AUTISM IS A NEUROBEHAVIORAL SYNDROME resulting from a dysfunction of the central nervous system that leads to disordered development. According to the Diagnostic and Statistical Manual of Mental Disorders, 4th edition (DSM-IV), published by the American Psychiatric Association (1994, pp.70-71), the onset of symptoms in autism occurs within the first three years of life and includes three general categories of behavioral impairment common to all persons who have autism:

- Qualitative impairments in social interaction
- Qualitative impairments in communication
- Restricted, repetitive and stereotyped patterns of behavior, interest and activities

There are a number of other common findings in children 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.

In recent years, the conceptualization and criteria defining the condition called “autism” have evolved significantly. The definition of autism has broadened so that autism is now seen as a spectrum disorder. For these guidelines, the panel agreed to use the terminology of “Autism Spectrum Disorder (ASD) and “Pervasive Developmental Disorder” (PDD) which would include the disorders commonly diagnosed as Autism, Asperger Disorder, Rett Syndrome, Childhood Disintegrative 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 may be more common than previously realized, particularly if the broader definition of autism as a spectrum disorder is used to determine the number of cases. Earlier studies suggested that the prevalence of autism is about three to four individuals in 10,000, but more recent studies have suggested higher rates for the general class of ASD/PDD, up to or greater than sixty in 10,000. The higher estimated rates reflect inclusion of the broader range of autism, including milder subtypes on the spectrum (PDD-NOS and Asperger Disorder). The apparent increase may also be a result of improved diagnosis, but a real increase in prevalence cannot be absolutely ruled out.

DEFINITION OF AUTISM

Educational Definition (IDEA) - Federal Regulation–34 CFR 300.7(c)(1)

- I. Autism means 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.

Ohio Definition

Adopted Federal Definition.

Autism Society of America Definition

Autism is a complex developmental disability that typically appears during the first three years of life. The result of a neurological disorder that affects the functioning of the brain, autism impacts the normal development of the brain in the areas of social interaction and communication skills. Children and adults with autism typically have difficulties in verbal and non-verbal communication, social interactions, and leisure or play activities.

Autism is one of five disorders falling under the umbrella of Pervasive Developmental Disorders (PDD), a category of neurological disorders characterized by "severe and pervasive impairment in several areas of development," including social interaction and communications skills (DMS-IV-TR). The five disorders under PDD are:

- Autistic Disorder
- Asperger Disorder
- Childhood Disintegrative Disorder (CDD)
- Rett Disorder
- PDD-Not Otherwise Specified (PDD-NOS)

Each of these disorders has specific diagnostic criteria as outlined by the American Psychiatric Association (APA) in its *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR)*.

Medical Definition (from DSM/IV)

Autistic Spectrum/Pervasive Developmental Disorder

Categories and Diagnostic Criteria

Overview of Autism Spectrum Disorder

ASD/PDD is a group of conditions with common dysfunction in the domains of socialization and communication. These include Autistic Disorder, Asperger Disorder, Rett Syndrome, Childhood Disintegrative Disorder and Pervasive Developmental Disorder-Not Otherwise Specified.

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

- **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 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 Disorder** has a less severe impairment in socialization with difficulties interpreting social cues and naive/peculiar behavior. Language, while normal in achievement of developmental milestones, has associated problems in abstraction, interpretation and pragmatics. Areas of fascination are usually cognitively based. By definition, individuals with Asperger Disorder have borderline to normal intelligence and most have problems with fine and/or gross motor function.

- **Rett 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 Syndrome is caused by an abnormality in the MECP2 gene on the X chromosome.
- **Childhood Disintegrative Disorder** has behavioral features similar to autistic disorder 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.
- **Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS)** is applied to children who have some, but not all, of the features of autistic disorder (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.

MEDICAL ASPECTS

Introduction

This section describes issues related to diagnosis and medical concerns for individuals with ASD/PDD. 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, such as anxiety, tics, and mood disorder. This section is best used in conjunction with the rest of the document, because medical interventions alone may not be sufficient to change behavior or to maximize learning. It is, however, important to address potential medical problems, because they can limit all other areas of development.

Screening and Diagnosis

Screening of all toddlers for a possible diagnosis of ASD/PDD is recommended. Because there are few, if any, well-validated screening tools for ASD/PDD in the school-age population, those who are exhibiting a concerning combination of language, social and behavioral difficulties are candidates for a more detailed evaluation. At risk children include those with social-pragmatic language difficulties, circumscribed intense interests, and significant dysfunction in social interaction.

Medical Key Points:

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

Evaluation of the school-age child for a possible ASD/PDD diagnosis does not differ significantly from the evaluation of the preschooler. The child should be referred for an evaluation by a medical professional familiar with ASD/PDD. These professionals include child neurologists, psychiatrists, and developmental pediatricians. A complete history and physical examination should be performed, with emphasis on family history of individuals with similar difficulties, information from previous evaluations, and physical findings suggestive of other medical/genetic conditions. Since some medical disorders are associated with or appear similar to ASD/PDD, the medical evaluation is needed before any definitive diagnostic statement regarding ASD/PDD is made.

Medical lab testing can be helpful in defining an underlying etiology for ASD/PDD, although an identifiable cause is present in only a small percentage of this population. Most children will have already been evaluated in the preschool years. For those who have not been diagnosed or have had no medical assessment, the following is recommended.

1. **Chromosomal Analysis.** Up to 5% of individuals with autistic spectrum disorders have an identifiable chromosomal abnormality; therefore, all children should have high-resolution chromosomal analysis and DNA test for Fragile X syndrome.
2. **Electroencephalography (EEG)** is not a routine study in this population. This test is indicated in individuals who have 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. 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 epileptiform activity.
3. **Hearing and Vision Screens** in all children.
4. **Other tests** should be ordered as clinically indicated and not because of the diagnosis of ASD/PDD. Children with developmental/cognitive impairment and ASD/PDD may be candidates for testing for inborn errors of metabolism, including amino acid and organic acid assays. Other studies such as allergy testing, immune workup and heavy metal assays should be done only if there are clinical features of these types of disorders.
5. **Lead levels** should be considered for children with ASD/PDD and excessive mouthing behavior or Pica.
6. **Evaluation of Gastrointestinal Dysfunction.** Despite anecdotal reports, no causal relationship has been established between gastrointestinal dysfunction and ASD/PDD. Since individuals with ASD/PDD can have GI dysfunction of diverse etiology (such as gastroesophageal reflux, disaccharidase deficiency and excessive juice intake), the evaluation should be based on the clinical presentation and not necessarily on the diagnosis of ASD/PDD.
7. **Brain MRI** rarely shows any significant abnormality in individuals with ASD/PDD unless there is a co-existing condition. Therefore, MRI is recommended only for appropriate clinical indications such as microcephaly, macrocephaly, seizures or focal neurologic features.
8. **Brain Neuroimaging for Childhood Disintegrative Disorder.** Individuals with childhood disintegrative disorder should have an evaluation that includes brain neuroimaging, awake and sleep EEG, detailed metabolic testing and other tests as indicated by the history and clinical presentation.

Similar to the preschool age child, the diagnostic assessment of a school age child should occur through a multidisciplinary approach. In addition to the medical evaluation, school age children should undergo formal psychological assessment by a child psychologist experienced in evaluating children with ASD/PDD. As a component for this assessment, the use of well-recognized diagnostic tools is imperative because of the presence of subtler symptomatology in this age group. Evaluation is necessary by a speech/language pathologist with expertise in assessing children with ASD/PDD, even in a child with apparently normal speech, in part to examine social and pragmatic skills.

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

The school has a role in the diagnostic assessment of a school-age child for possible ASD/PDD. 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 family is an essential member of the diagnostic team. Family members contribute by providing the important historical information. They can optimize their role by becoming familiar with the features of ASD/PDD and helping the diagnostic team recognize the features that may or may not be present in their child.

Diagnostic/Screening Instruments

The following instruments are used to diagnose or assess the clinical course of children with ASD/PDD. They measure function and dysfunction across the various areas of ASD/PDD. 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.

DIAGNOSTIC TOOLS

Childhood Autism Rating Scale - (CARS)

CARS is a well-validated tool for the diagnosis of ASD/PDD. Its 15 items include 14 specific domains plus one category of “impression of autism.” It is based on a rating scale from 1 to 4 that is scored with information from parent report, available records, and observation of the child. Training videos are available (Schopler, Reichler, DeVellis, & Daly, 1988; Schopler, Reichler, & Renner, 1986).

Autism Diagnostic Interview - Revised - (ADI-R)

The ADI-R is a standardized, semi-structured, investigator-based interview of individuals with ASD/PDD. It can be used for children with mental age of or above eighteen months. There is good supporting research to confirm its reliability and validity. It takes several hours to administer and score. Primarily, it is a tool for use in research studies (Lord, Rutter & Le Couteur, 1994 in the *Journal of Autism and Developmental Disorders*).

Autism Diagnostic Observation Scale - (ADOS)

The ADOS is a structured observation schedule for the diagnosis of ASD/PDD. 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 (prelinguistic-ADOS). Since it is used in a highly structured environment, it may not reflect the most severe or obvious features of ASD/PDD; therefore, observations in non-structured settings and parent interview may be necessary (Lord et. al., 2000 in the *Journal of Autism and Developmental Disorders*).

Gilliam Autism Rating Scale - (GARS)

The GARS is based on the DSM-IV definitions of ASD/PDD 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 & Janes, (1995), AGS Publishing).

Asperger Syndrome Diagnostic Scale - (ASDS)

The ASDS is a quick, easy-to-use rating scale that can help determine whether a child has 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/no items in 10 to 15 minutes. Designed to identify Asperger Disorder in children ages five through eighteen, this instrument provides an AS Quotient that tells the likelihood that an individual has Asperger Disorder (Myles, Beck, Simpson, (2001), Pro-Ed).

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 CARS or ADI-R (From Krug, Arick, and Almond (1978)).

Autism Screening Instrument of Educational Planning (SECOND EDITION, 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/PDD features (David A. Krug, Ph.D., Joel R. Arick, Ph.D., and Patricia J. Almond, Ph.D., (1993), Western Psychological Services).

Checklist for Autism in Toddlers - (CHAT)

The CHAT is a brief checklist to screen for ASD/PDD in children at or above the age of eighteen months. It has two components:

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

Two studies have validated its usefulness as a screening tool for children with full features of ASD/PDD and, to a lesser degree, for children with high-functioning autism or Asperger Disorder (Checklist for Autism in Toddlers. Adapted from Baron-Cohen S, Gillberg C. Can autism be detected at eighteen months? The needle, the haystack, and the CHAT. *Br J Psychiat* 1992;161:839).

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.

First Signs Program

The First Signs educational and training program incorporates an integrated mix of mailings, public service announcements, press activities, training, research, and website at www.firstsigns.org, which provides 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 American Academy of Pediatrics, highly validated developmental and autism screening tools, a pediatrics practitioner's referral guide to Early Intervention, and a developmental milestone 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 developmental and autism, are evaluated constantly.

Parents Evaluation of Developmental Status (PEDS) is a parent questionnaire which is 70 percent 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.

Ages and Stages Questionnaire (ASQ), developed by Diane Bricker, Ph.D. and Jane Squires, Ph.D. identifies children 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.

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 from six through twenty four months of age.

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/PDD. It consists of a checklist of core areas of dysfunction and ASD/PDD 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 (Bryna Siegel, Ph.D., (2001) University of California, San Francisco).

Psychoeducational Profile - Revised

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. The Adolescent and Adult Psychoeducational Profile (AAPEP) extends the PEP-R to meet the needs of adolescents and adults (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 and Schopler, (1988), Pro-Ed).

FUNCTIONAL ASSESSMENTS

Real Life Rating Scale

The Real Life Rating Scale 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 (RLRS, Ritvo, Freeman, Yokota, & Ritvo (1986).

Medical Intervention for Individuals with ASD/PDD

Autistic Spectrum Disorders are now recognized as neurobiologically based conditions. Individuals with ASD/PDD require ongoing medical monitoring and care, as would any person with a chronic medical condition. All treatments - medical and non-medical - should be reviewed at every visit. The frequency of this monitoring should be individualized to the child's specific needs. This care should occur under the supervision of a medical professional, such as a child psychiatrist, general or developmental pediatrician or pediatric neurologist, with expertise in working with children with ASD/PDD. It includes monitoring a child'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.

The role of the medical practitioner starts with appropriate identification and continues with medical testing for potential underlying etiologies and monitoring for co-morbid conditions and their treatment.

Medical areas to be addressed include:

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/lacerations. Absence of a sense of danger can place the individual in potentially harmful environments. Monitoring and preventive anticipation are important.

SLEEP

Sleep difficulties are quite common in individuals with ASD/PDD, occurring in up to 70%. These include problems with sleep onset, night waking, and early waking. Sleep problems can be behavioral in nature, reflective of an underlying organic disorder or a combination of both. Because sleep problems can disrupt family life, they should be addressed aggressively. Behavioral strategies to ensure good sleep hygiene should be established. Medical interventions for individuals who have organic sleep disorder include further testing and possible use of medications. Since seizures can disrupt sleep, an EEG should be considered in the appropriate context.

FEEDING/NUTRITION

Individuals with ASD/PDD 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, increased sensory sensitivity, 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), coprophagia 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 (SLP, OT, psychologist, registered dietitian, nutritionist, etc.) who has experience working with feeding issues in these children.

STEREOTYPIES

Simple repetitive behavior characterizes much of the play of young children with ASD/PDD. 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/PDD and multiple, often undiagnosed, sensory deficits and those with greater degrees of mental retardation. They are often not responsive to medication.

SEIZURES

Children with ASD/PDD are at increased risk for the development of seizures with up to 20 - 30% prevalence by adulthood. The types of seizures are no different from the regular pediatric population. There should be a low threshold for obtaining an EEG on children who are exhibiting activity suggestive of seizures. Treatment with anticonvulsant medication depends on the seizure type and frequency, with decisions based on individual need.

DENTAL CARE

According to American Academy of Pediatrics 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/PDD. 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.

SENSORY ISSUES

Many children with ASD/PDD 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. *(For more information, refer to Sensory Motor Processing)*

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. *(For more information, refer to Sexuality)*

PSYCHIATRIC DISORDERS

The core diagnostic component of stereotyped, repetitive behavior and preoccupations, which can have obsessive-compulsive features, may be amenable to pharmacologic intervention. In addition, individuals with ASD/PDD 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.

Co-morbid disorders are other medical conditions that are associated with and occur in this population at a higher rate than the normal population. These include:

ATTENTION DEFICIT/HYPERACTIVITY SYMPTOMS

Impaired ability to attend to some portions of the environment is characteristic of children with ASD/PDD. This can be manifested by 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/PDD manifest more of these hyperactive and inattentive symptoms than others. Although attention-deficit/hyperactivity disorder (ADHD) diagnostic criteria exclude the presence of autistic disorder, the target symptoms may sometimes respond to the same treatments as ADHD in the general population.

ANXIETY

In addition to the impaired social interaction characteristic of ASD/PDD, 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.

OBSESSIVE/COMPULSIVE AND SEVERE RITUALISTIC PATTERNED BEHAVIOR

Compulsive behaviors and rituals are frequently seen in individuals with ASD/PDD. They can develop from narrow preferences or simple stereotypies. Excitement often accompanies ritualistic behavior. Attempts to obstruct or distract a person with ASD/PDD 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 and/or pharmacologic interventions.

SELF INJURIOUS BEHAVIOR

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

TICS

Tics are irregular, repetitive muscular contractions which may be patterned enough to result in apparently meaningful behavior. Tics vary greatly in severity. Some clinicians report a greater-than-chance co-morbidity of tics and Asperger Disorder or PDD-NOS. Mild, non-impairing tics need not be treated. More severe tics can be disabling and may respond to medication.

AGGRESSION

While a certain amount of aggressive behavior is common in all children at various ages, children with ASD/PDD tend to express these behaviors more frequently and with greater intensity. Tantrums are common in young children with ASD/PDD. 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. *(For more information, refer to Functional Analysis of Behavior and Behavior Interventions)*

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/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/PDD 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, disinhibition (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 cyclicity of behavior of any kind (such as aggression, bolting, SIB), often preceded by a few nights of unaccustomed sleeplessness. All individuals with suspected mood disorders should be referred for further evaluation and treatment.

Additional Interventions

MEDICATIONS

Like any treatments, medications should be reviewed at every follow-up visit. A variety of medications have been described for individuals with ASD/PDD and several have been researched; however, there is no one medication that works for every person with ASD/PDD. The medication treatment of an individual with ASD/PDD 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. 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. Occasionally, a trial of medication tapering and discontinuation is a way to determine its efficacy and/or whether it is still needed.

ALTERNATIVE THERAPIES

Interventions have been proposed based on theories of autism causation such as heavy metal poisoning, dietary factors, and auditory hypersensitivity. While anecdotal reports of intervention efficacy exist, there is no reproducible scientific research to support these claims of improvement outside of the possible impact of the placebo effect. If a trial of an alternative therapy is undertaken, one should ensure that the potential side effects will not harm the individual and that the trial will not impede the implementation of other proven treatments.

ESSENTIAL COMPONENTS OF INSTRUCTION

Considerations

This section describes different components of instruction that should be addressed with individuals with ASD/PDD from kindergarten through high school. It includes an explanation of the unique learning styles of individuals with ASD/PDD and considerations for creating effective learning environments. 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.

DEFINITION OF “CURRICULUM”

John Dewey referred to curriculum as ‘... a continuous reconstruction, moving from the child’s present experience out into that represented by the organized bodies of truth that we will call studies ...’ (The Child and the Curriculum, pp. 11-12). This definition remains applicable to today’s educational challenges. Building on Dewey’s main points, curriculum is defined as an organized program of instruction designed by a team of professionals that responds to the changing needs of individuals and supports them toward independence and lifelong learning. This definition does not refer to a specific methodology, commercial product or author’s invention.

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

- Matched to the strengths and needs of the individuals
- Modified as individuals change
- Effective in supporting independence and learning
- Aligned with state adopted content standards

LEARNING STYLES OF INDIVIDUALS WITH ASD/PDD

Individuals with ASD/PDD 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/PDD may exhibit varied skills (e.g., visual, memory, music). These strengths may dictate an individual’s most effective mode of learning.

Individual Interests: Individuals with ASD/PDD 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/PDD 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/PDD have unique communication abilities and difficulties that may impair the teacher in recognizing the effectiveness of the process. 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/understanding these sensations, and developing a response to them. Sensory systems include auditory, visual, tactile, proprioceptive, vestibular, olfactory, and gustatory. Individuals with ASD/PDD 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/PDD 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 for the individual to read social cues and the context and behave accordingly. Typically, social situations for individuals with ASD/PDD are often very stressful. Teaching techniques that rely on social situations may cause stress with individuals with ASD/PDD 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.

ISSUES OF ASSESSMENT

The purpose of assessment is to develop instruction appropriate to the needs of each individual. Federal and state guidelines require assessment in the following domains:

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

However, assessments of individuals with ASD/PDD 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 a multi-factored evaluation (MFE), need to take into consideration the unique learning style of the person with ASD/PDD (*reference section on Learning Styles of Individuals with ASD/PDD*). Assessments/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 individual, shorter test periods over multiple sessions, advance notice to individual prior to testing, and sensory motor preparation for optimal level of alertness.

(Reference IDEA Partnerships Council for Exceptional Children (CEC) document called "Making Assessment Accommodations: A Toolkit for Educators" (Document #P5376) and the sections on Communication, Sensory Motor Processing, Functional Analysis of Behavior and Behavior Interventions, and Community Transition)

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. (*Reference sections on Communication, Sensory Motor Processing, Predictability & Structure, and Generalization of Skills*)

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. (*Reference Functional Analysis of Behavior and Behavior Interventions*)

Focus of Intervention – All Ages

Federal law requires that 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/PDD will have specific goals and objectives that need to be addressed in order to participate and progress in the general education curriculum.

The following areas will 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 with one to two backup systems

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. Continued vocabulary building, comprehension and use

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
- e. Will be able to give help and accept help
- f. Choice-making
- g. Understanding other persons emotions and perspectives
- h. Interdependence – be able to assist and accept assistance from others

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/effect
- c. Abstract thinking
- d. Humor

PURPOSEFUL PLAY/RECREATION/LEISURE

Purpose – Enhance cognitive, social and motor skills; enhance relationships between self and environment and improve appropriate use of unstructured time

Target Areas:

- a. Intentional and systematic introduction of a variety of play and leisure skills
- b. Interaction/cooperation with peers
- c. Leisure to include toys, games, sports, hobbies, creative arts (drama, music, writing, arts and crafts)

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/drinking
- c. Safety
- 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

Additional Focus Areas – Ages Six Through Twenty One

In addition to the above areas, the following areas should be included in programs for individuals, ages six through twenty one:

TRANSITION (REFERENCE COMMUNITY TRANSITION SECTION)

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 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

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 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 a repertoire of expected social behaviors for environments where the individual lives, learns, works, and spends leisure time
- c. Develop skills and abilities which lead to positive and acceptable behaviors

Essential Components of an Instructional Program

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

Key Areas:

- ***Earliest intervention***
- ***Intensity***
- ***Predictability and Structure***
- ***Generalization***
- ***Functional Analysis of Behavior***
- ***Communication***
- ***Assistive Technology***
- ***Sensory Motor Processing***
- ***Social Development***
- ***Integration with Typical Peers***
- ***Assessment of Progress***
- ***Transition***
- ***Sexuality***
- ***Lifelong Support***

The purpose of the following section is to provide educators, administrators, individuals, and families with a framework and structure for program development and evaluation.

EARLIEST INTERVENTION

The standard “earlier is better” may serve as a particular advantage for children with ASD/PDD (Lovaas, 1987; McClannahan & Krantz, 1993); however, identifying and diagnosing ASD/PDD at any age allows professionals and families to address the challenges associated with ASD/PDD 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/PDD and their families:

- Provide the opportunity to intervene to minimize the development of interfering behaviors and/or 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/PDD, 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/PDD and the family in intervention planning and implementation to promote generalization and maintenance of skills.

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 individual 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/PDD.
- Provide individuals with ASD/PDD continuity of programming across people and settings as agreed upon in the IEP or IFSP.
- Recognize that effective intervention for ASD/PDD requires ongoing assessment and ongoing individualized programming.

PREDICTABILITY AND STRUCTURE

Individuals with ASD/PDD 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).
- Pairing routines, activities and transitions utilizing an analog clock.

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.
(*Reference Sensory Motor Processing*)

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) 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.

GENERALIZATION OF SKILLS

Typically, young children/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/PDD, 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/PDD.

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/PDD 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.

FUNCTIONAL ANALYSIS OF BEHAVIOR AND BEHAVIOR INTERVENTIONS

This section describes issues related to the behavior of individuals with ASD/PDD. 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/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/PDD 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/PDD. 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 (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). Teachers and caregivers need to view behaviors as communicative rather than an intentional effort to disrupt.

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.

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

Functional Analysis of Behavior and Behavior Interventions

The premise of a Functional Behavior Analysis (or Assessment) is that all behavior serves a purpose. Behavior often achieves some desired goal or goals. The goal or goals may be escape/avoidance, control (including meeting one's own sensory needs), attention, and/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/PDD 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/PDD.

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/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.
- 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 reinforcer effectiveness 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.

(For detailed information regarding Functional Behavior Assessment, please see Appendix IV)

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.

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/PDD. 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/PDD. 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.

Influences on Behavior

Behaviors are influenced by the characteristics of ASD/PDD and by environmental issues.

Some behavioral influences include:

Stress/Anxiety – Stress and anxiety are often key factors triggering behaviors characteristic of people with ASD/PDD. 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/PDD may view causes of stress differently and have varied reactions to stress. All caregivers/providers must be aware of and manage their own stress levels. Individuals with ASD/PDD 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/PDD 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/PDD 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/PDD 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 (e.g., 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.

SOME COMMON BEHAVIORAL BARRIERS IN ASD/PDD

CHALLENGING BEHAVIOR	DEFINITION	EXAMPLE	INTERVENTION	COMMENTS
Ritualistic & Compulsive	Highly repetitious activities. Often used to structure time and interests.	Repetitive hand washing. Touching objects.	Intervene early, before the habits are strengthened. Teach meaningful alternatives that are incompatible with ritualized behaviors. (e.g., structure when hand washing should occur; cue stopping with a timer)	Sometimes these rituals can be beneficial. Often ritualistic behaviors interfere with appropriate activities in severe cases. It sometimes takes years to fade a ritualistic behavior.
Impulsivity	Disruptive behaviors resulting from a strong need to do something combined with the lack of social perspective of how behavior impacts others.	Diving to remove a piece of lint from the floor; stealing coffee at the bowling alley; public stripping; sexually motivated behaviors.	Manage environment to limit tendency while systematically teaching the individual to stop, think, and make decision. Use of <i>Social Stories</i> , teaching social skills, and rehearsal of appropriate alternatives.	Impulsive behavior issues may result in compromising the safety of the individual.
Stereotypic	Behaviors involving physical movements that seem to serve no purpose.	Flapping arms, flicking fingers, rocking, etc.	1. Have an OT evaluate 2. Present appropriate sensory alternatives that offer the same sensory benefits but with fewer negative consequences. (e.g., swinging, trampoline, squeezing "kush" ball, or playdough) Refer to Sensory Motor Processing.	These behaviors may serve more of a self-regulatory function (e.g., sensory input) rather than any function that is apparent to others.
Aggression	Aggression may be toward self (SIB: Self Injurious Behavior) or others.	Banging head with hands or against walls; picking skin until it is damaged; targeting individuals to hit or kick.	Analyze stressors in the environment, e.g., schedule changes, noises, irritants, etc. and remove them or structure for comfort and clarity. Redirect harmful behaviors. Offer alternative "rules" or activities.	Persons with ASD/PDD often respond to stressors in their environment by acting out towards themselves and/or others.
Inappropriate Social Interactions	Ranges from complete indifference to others, to socially inappropriate.	Invading personal space; social isolation; inappropriate comments.	Train with a script for social interactions. Reward appropriate behaviors. Use <i>Social Stories</i> (seea Carol Gray). Refer to Social Development.	Persons with ASD/PDD often lack social perspective resulting in asocial or inappropriate social interactions.

This represents a sampling of frequently encountered behaviors and suggested strategies. These should not limit other creative alternatives that consider the uniqueness of each individual.

COMMUNICATION

The Communication section describes the unique patterns of communication associated with individuals with ASD/PDD. 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. The ability to communicate one's feelings and thoughts to others has a profound effect on quality of life both immediately and longterm. 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/PDD 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 both verbal and nonverbal are inherent to the diagnosis of ASD/PDD. The normal developmental sequence of communication development is disrupted in persons with ASD/PDD. 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.

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

It is important to understand the individual's unique communication style/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

- Decrease question asking and increase comments and descriptions of activities, emotions, and environments that the person experiences.
- 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.

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). 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.

The varied use of technological systems with individuals with autism spectrum disorder has received limited attention in spite of the fact that technology tends to be a high interest level for many of these individuals (Stokes, Wirkus-Pallaske, and Reed. (2000) Wisconsin Assistive Technology Initiative). 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. 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

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.

SENSORY MOTOR PROCESSING

This section describes issues in sensory motor processing for individuals with ASD/PDD. 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/PDD 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/PDD 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), we may have difficulty paying attention and formulating responses that make sense. In addition, we 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/PDD 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 individual's tolerance/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/unstacking, 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.

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.

SOCIAL DEVELOPMENT

Impaired social development is a cardinal feature of ASD/PDD. It ranges from complete indifference to others to atypically social to socially inappropriate. Social development is dependent on other areas of

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/PDD.

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 as well as improving the quality of life.

The social deficits in ASD are influenced by the individual's age and severity of impairment. Usually the deficits 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 co-morbid conditions. Social impairment has been defined by Lorna Wing as:

1. **Socially aloof** – ignore or avoid social interaction with indifference to peers and limited if any, response to simple stimulation.
2. **Socially remote** – little spontaneous social interaction with allowance of social approaches and limited passive involvement in activities.
3. **Active, but odd** – Attempt social approaches to achieve personal goals (needs or area of fascination) with little interest in the needs or responses of others.
4. **Superficially social** – Utilizes learned social scripts with ongoing deficit in true grasp of social rules and impact of actions.

These classifications are based on clinical observations. From a functional standpoint, they provide a basis for differentiating social impairments and monitoring an individual's growth over time.

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/PDD.

There are several levels to consider when providing social strategies and supports. When assessing the social competence for individuals with ASD/PDD, 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 Disorder 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

(See Appendix IX – References and Resources, Social)

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

- Imitation and joint attention (attending with others)
- Understanding personal space
- 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
- Asking for help/assistance
- Slang, sarcasm, joking, teasing
- Initiating, maintaining and reciprocating social interactions
- Accepting rejection by peers
- Playing games, winning and losing graciously
- Turn-taking, waiting for turn
- The meaning of body language (includes facial and bodily gestures)
- 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/PDD
- 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/PDD "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/PDD 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/PDD 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

(For a complete list of resources, refer to Appendix IX References and Resources, Social)

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.

INTEGRATION WITH TYPICAL PEERS

(This section is not intended to be used for Least Restrictive Environment decisions).

Models of language and social interactions are an important component of a successful program for individuals with ASD/PDD; 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/PDD in integrated activities, consider the following guidelines:

- Assess the person's individual need for integration with typical peers. Provide a natural progression of integration (e.g., individual to segregated classroom to small group to large group instruction).
- Plan and schedule activities that promote integration and prevent segregated grouping.
- Continue to emphasize the acquisition of skills that will allow the individual to benefit from integration 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/PDD. 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.
- Determine the amount of time the individual should spend in the integrated setting.

ASSESSMENT OF PROGRESS

Assessment is vitally important for judging the effectiveness of any intervention. Progress assessment is especially critical for the population with ASD/PDD, because they are resistant to many forms of intervention that are very effective with others. Therefore, treatments used for those with ASD/PDD should be held to standards of effectiveness and appropriateness that respect the values of parents and professionals to make a difference in the lives of these individuals.

The outcome of any intervention can be assessed in two ways:

- a. **Criterion Referenced** – This method is useful when the desired outcome is known and well understood. Using a criterion-referenced approach to evaluate progress tells everyone that effective intervention has occurred when the goal is successfully achieved. In criterion references assessment, the various levels of evaluation must be considered carefully. The overall intervention program or strategy is judged on the basis of the achievement of the entire collection of goals and objectives. Progress on goals is assessed on the basis of achieving the interim objectives leading to their individual completion. Example: Can a child tie his own shoes?
- b. **Norm Reference or Standardized** – Intervention can be judged in terms of change in a desired direction from some defined starting point according to some accepted standardized measure. This method of progress assessment makes it necessary to define the reference points very carefully. Progress is then determined on the basis of change in some or all of these measures. The minimum number of measures needed is two, once at the start of treatment and once at the end of the evaluation period. Example: Improvement in communication skills over a fixed period of time as measured by the Preschool Language Scale (PLS).

Criterion referenced and norm referenced assessment are often combined in practice. Anecdotal observations should be used to support but not replace objective and quantitative data.

TRANSITION

Individuals with ASD/PDD 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 and family, certain steps need to be taken to make the transition as smooth and problem free as possible.

The following provides guidelines for accomplishing successful transition.

- Awareness of the problem and appropriate planning are key to making successful transitions for individuals with ASD/PDD. 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. Once the circumstance is understood, the plan for supportive, preventive measures can be put in place.

- Individuals with ASD/PDD should be informed several times before difficult transitions are made by explaining in terms they understand, “when” and “what” the transition will be. 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, e.g., the individual, the family, and the teacher. The teacher should attempt to know as much about the individual as possible before the transition. This is particularly important for individuals with ASD/PDD, because many teachers have limited experience with these individuals, and individuals with ASD/PDD vary widely in their educational needs. The family and the individual may also need increased supports for making this a successful transition, and the planning and resources for this should be available before the transition occurs. It may be helpful to have the individual and parent visit the new classroom and teacher before classes begin. 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.

Proactive planning, which begins by the fourteenth birthday or earlier, is the key to a positive outcome and obtaining a job.

- 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. (*Reference Community Transition*)

SEXUALITY

This section describes issues relating to the sexual development of individuals with ASD/PDD. 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/PDD 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/PDD pose many challenges in the classroom, the community and at home. These same challenges may cause difficulty for the individual with ASD/PDD in the expression of sexuality. Often the individual's behavior is misunderstood by others. Knowledge of the characteristics of ASD/PDD 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/PDD must address the issues of 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). An ongoing hierarchy of skills training should be included in any educational program for individuals with ASD/PDD. 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/PDD need to:

- Have the opportunity to make friends
- Learn skills that will assist in making friends
- Care for their own 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/PDD 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/PDD. It is clear, however, that many persons with ASD/PDD 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 illegal 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/PDD

- a. Public or inappropriate displays of sexual behaviors (exposing self, public masturbation, etc.)
- b. Self-injurious masturbation
- c. Social contact/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, therefore, to address sexuality will include a broad range of issues and objectives.

A **holistic** approach will consider all aspects of social preparedness for relationships and needs to include:

- 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/PDD 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/PDD 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/PDD 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/PDD. *Social Stories*, the work of Carol Gray, provides a non-threatening vehicle for rehearsal of appropriate behaviors. *Rules scripts* as described by Mirenda & 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/PDD.

LIFELONG SUPPORT

The mandated educational services for individuals with disabilities including ASD/PDD 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/PDD 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.

Supports may be needed in the areas of:

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

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 that 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-blank answers for the individual that 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 that has difficulty working in groups to "instant message" with teacher/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.

COMMUNITY TRANSITION

This section builds upon the previous sections by focusing on preparation for and transition to life beyond high school. In this transition, individuals with ASD/PDD leave an entitlement system and enter systems based instead on eligibility. 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.

Three 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***

This section 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 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.

Within this section, the user will first find the three basic principles of transition. Also included are additional components to assist in the transition process and practical tips for success. This information is useful whether the individual transitioning will go to work or post secondary classes following the school years.

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

THREE BASIC PRINCIPLES OF TRANSITION:

- 1) Start early.
- 2) Involve all service agencies and funding sources.
- 3) Have a job before graduation that can be retained or secure post secondary education options.

SCHOOL TO ADULTHOOD

Overview

Transitioning from school to adulthood is a process of preparing a person with ASD/PDD to be part of their 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. In order to make the vision a reality, 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/PDD, this transitioning process may take longer and, after it occurs, may require that the individual 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 interests, strengths, skills and barriers for the individual who will make the journey.
- Include pragmatic, person-centered, individualized strategies which focus specifically on the vision. These strategies should support outcomes which will occur in the community.
- Develop collaborative efforts between 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” process.
- Assess progress at each stage. Reset tactics, funding, and supports when necessary.
- 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/adult service provider agencies regarding the transition process, people/agencies involved, financing systems, etc. This should include the benefits of community employment vs. sheltered employment and post secondary education options.

Practical Tips for Transitions to Work after High School

GETTING PREPARED

- Behavior needs to be understood, managed and appropriate for the expected outcomes.
- The individual needs a communication system with one or two back-up systems that allows the individual to engage in functional/reciprocal communication.
- 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. Some of these include, but are not limited to, RSC/BVR/BSVI/BDD, ODMR/DD, ODJFS, ODH, ODMH, Social Security, and Employment Networks. Each organization, if invited, can explain the process to access agency services, as well as eligibility criteria.
- 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 tryout should be viewed as helpful in learning about the types of supports the individual needs and their work preferences.
- Focus on abilities not disabilities, and 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.

- The high school should develop job skills and supports designed to meet individual and employer needs. Matching abilities with the needs of a business drives job development. It is helpful to answer the following questions during this process: Which jobs match the individual's abilities? What weaknesses are liabilities to placement? How can these challenges be overcome?
- 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.) that are needed for lifelong support. In the final school years, transition goals will drive the IEP.
- 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.

REACHING OUT

- When determining an individual's learning or work potential, utilize ecological assessments in the community that are meaningful to the individual in light of expected outcomes.
- Take 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.
- Investigate places in the community that offer volunteer experiences and use them for job sampling such as:
 - a. Public libraries
 - b. Nursing homes
 - c. The Humane Society
 - d. Public Television
 - e. Hospitals
 - f. United Way Agencies
 - g. YMCA Programs
 - h. Public Radio
 - i. Local Universities
- 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. Its 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 IEP.
 - 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. The Ohio County Boards of MR/DD
 - b. The County Department of Job & Family Services
 - c. The Social Security Administration
 - d. The Rehabilitation Services Commission
 - e. The Ohio Department of Mental Health
 - f. The Ohio Department of Health
 - g. The Alcohol, Drugs and Mental Health Board (ADAMH)
- 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 of the individual working
 - c. Letters of recommendations from supervisors/employers
 - d. List of job skills
 - 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.
 - 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. 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/PDD require long-term or ongoing supports. Plans should then include identification of funding for these supports.

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 coaching, natural supports, behavior support and modification, funding sources and uses, interviewing skills, employer expectations, 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. County Boards of MR/DD
 - b. Residential Services Providers
 - c. Real Estate Firms
 - d. Home and Apartment publications
 - e. The Internet

It should be emphasized that residential services often involve long waiting periods and should therefore 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 may wish to pursue a job after high school, which requires additional education. When this occurs, the IEP and transition plan should support this vision. Preparation should then begin for post secondary learning.

Under the Individuals with Disabilities Act (IDEA), 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 services that were once provided for them.

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

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 an individual with a disability. He 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.
- Individuals 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 how to request needed accommodations and supports.
- Individuals should visit and/or audit classes from desired schools.
- University or college professors are not informed of the 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 technology which might support individual learning and participation, e.g., computer software.
- Consider taking the SAT and ACT 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 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.

FAMILY INVOLVEMENT

This section describes the importance of collaboration between families, 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/PDD. 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 to 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, teachers, medical professionals and other professionals share the responsibility of meeting the needs of an individual with ASD/PDD. There must be ongoing collaboration and communication with family members, professionals and community members. Optimally, it is a partnership where everyone's contributions are valuable. 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 job, 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/PDD, it is more advantageous for all parties to freely and openly share these challenges and barriers to assure the most creative outcomes.

As the individual with ASD/PDD 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 that 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.

Communication between home and school is critical. Many individuals with ASD/PDD 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 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 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/PDD to communicate and his or her age. Commonly used methods include notebooks passed back and forth, home visits, phone calls, email, and scheduled visits to the school by parents/caregivers.
- Families and professionals should frequently share successes, progress, and strengths of the individual with ASD/PDD, 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 child 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 design of the individual's program, including through the IEP process. After the age of fourteen, this will include transition planning as well.
- Because individuals with ASD/PDD typically require lengthy planning and training for transitioning from school to work, the transition visioning process should be encouraged before age fourteen.
- 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

- Families and professionals should be provided with opportunities to access information about ASD/PDD, 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/PDD 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 individual's 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).

PROFESSIONAL AND COMMUNITY DEVELOPMENT

This section describes the need for training a wide range of people including professionals, paraprofessionals, college personnel and students, families and community members who support individuals with ASD/PDD. 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/PDD will be able to access needed supports and services.

Educational and awareness opportunities are essential for professional and community members that provide support and education to individuals with ASD/PDD.

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, when at all possible, occur prior to their involvement with the individual with ASD/PDD. Training should focus on skill building as well as empowerment, problem solving, collaboration, and decision-making. Training should encompass the entire spectrum of ASD/PDD.

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/PDD, 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 lecture, workshops, conferences (state, local, professional), group study/discussion, undergraduate and graduate coursework, mentoring, demonstration, action research, dissemination of print and multimedia resources, interactive distance learning and internet access, hands-on experience, guided practice, observation, and consultation.

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

- Characteristics of ASD/PDD 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
- The ASD/PDD spectrum disorder as it relates to individual's differences in learning and development
- Adaptation of the curriculum
- Developing communication
- Augmentative communication

- Classroom organization and/or environment
- Current legal issues
- Current research
- Family and professional partnership
- Functional analysis of behavior/applied behavioral analysis
- Transitions (e.g., home to school, between activities at school, school to work)
- Sensory processing problems
- Motor planning
- Writing and implementation of an effective behavior plan/behavior management
- Enhancement of social interactions
- Environmental supports to promote independence
- Understanding of play and engagement
- Available resources including relevant journals, films, books, articles, and videotapes as well as community resources like autism supports 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), 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, paramedics, etc.), mental health service providers, parents and caregivers. Training and professional development plans have evolved into critical pieces of any effective program.

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/community members and aligned with the needs of the individuals with ASD/PDD and their families.

Community persons should also participate in training regarding ASD/PDD. 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, 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/PDD (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 ORSC/BVR, County Board of MR/DD, Residential and Job Coaching vendors, Social Security, Medicaid etc., are examples of groups, as are local college administrators, who deal with special needs individuals in post-secondary settings.

Information in the field of ASD/PDD 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.

APPENDICES

I. LEAST RESTRICTIVE ENVIRONMENT (LRE)

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

First, it mandates that “schools must educate individuals with disabilities with children who do not have disabilities to the maximum extent possible.” Second, the LRE 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.

This concept includes six models of service delivery:

- **Shared classroom** - one classroom for both children with disabilities and children without disabilities
- **Integration** - enrolls several typical peers into the special education class to encourage an integrated setting
- **Mainstreaming** - children with disabilities are integrated into regular classrooms for specific class sessions or for part of the day
- **Reversed mainstreaming** - the service delivery integrates typically developing children into special education classrooms
- **Separate class in a public school** - this special class does not plan interaction with typically developing children
- **Special, non-public day or residential program** - for children who need a more intense education setting

Another way of supporting a child in a LRE would be by including an itinerant teacher who is a consultative resource to the regular education teacher in order to help the child succeed in the regular education environment.

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.

II. INCLUSION

Inclusion is defined as providing specially-designed instruction and supports for individuals with special needs in the context of regular settings. Inclusion reflects a philosophy of acceptance, belonging and community. It means that all individuals in a community are full members of that community, and each individual participates equitably in the opportunities and responsibilities of the general environment.

Inclusive education means that all individuals in a school, regardless of their strengths or weaknesses 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/PDD 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.

Special education is not a place. It is, however, identified as specialized instruction, supplementary aids, and services which are provided to individuals with disabilities who need specialized instruction. Some individuals (labeled as receiving special education or not) may need or want to spend some of their time learning in a quieter place with fewer people or with additional help from others.

It is important to clarify that inclusion does not simply happen when individuals are placed together in typical situations and that inclusive activities may occur for individuals that need a modified environment as part of their day. Appropriate supports and peer training are necessary to successful inclusion.

Inclusion may look different for different individuals. One option to foster inclusion is to place individuals with disabilities in the same setting as non-disabled peers. Peer mentors, “reverse” inclusion (including non-disabled peers with individuals with disabilities), and inclusion with peers for selected activities are also ways of providing a community experience. In many situations it is not the activity (curricular, extra-curricular, or community-based) that is important. Instead, when well-planned, activities may foster the philosophy of acceptance, belonging and community to all participating in that activity.

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 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.

Additionally, the estimated national cost of unemployment caused by excluding people with disabilities from the workforce is \$300 billion annually. In the community, people with disabilities and their families control millions of discretionary dollars. They enjoy sports, concerts, shopping, eating out and traveling. Accessible places and welcoming attitudes provide opportunities for all to share the benefits of economical and cultural growth. This makes inclusion important to everyone.

III. DEVELOPMENTALLY APPROPRIATE PRACTICE

The principles described as “developmentally appropriate practice (DAP)” by the National Association for the Education of Young Children serve as the theoretical background for programs for children. Because of the unique neurodevelopmental differences of children with ASD/PDD, however, narrow interpretations of some DAP principles can result in ineffective curriculum and teaching methodologies. Adaptation to the needs of children with ASD/PDD is necessary.

Children with ASD/PDD show highly uneven patterns of development across domains rather than the close interrelationship among domains described in DAP. Consequently, intensive teaching in areas of special deficit, particularly language and social behavior is typically required. These interventions may need to be at a level other than what might be appropriate for an individual’s chronological age.

Children with ASD/PDD frequently show little intrinsic motivation to learn developmentally appropriate concepts and behaviors, and they often have restricted interests. Extrinsic reinforcers are typically necessary to bring children to a level at which learning “for its own sake” becomes motivating.

Play in children with ASD/PDD is typically concrete, perseverative, and lacks symbolic features. Children with ASD/PDD require direct instruction in purposeful, appropriate solitary play, pretend play, cooperative play, and sociodramatic play with peers for play to become a vehicle for further learning and socialization.

Although the DAP suggests that children “construct their own understandings from their experiences,” unstructured time for children with ASD/PDD is often unproductive and may be filled with repetitive, stereotypic behaviors. Adult-directed structuring and interpretation of experience is required to establish foundation skills that enable children to become active learners. As the child progresses, planned opportunities to learn incidentally from teachers and peers become increasingly important for independence and generalization.

IV. 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 functional behavior assessment 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/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 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?

V. TRENDS AND OUTCOMES IN THE EMPLOYMENT OF PERSONS WITH DISABILITIES AND IMPLICATIONS FOR SCHOOLS AND THE MEDICAL COMMUNITY

In the statistical information below, we are presenting the state of employment for people with disabilities. This includes those with the most severe ongoing disabilities. This class, the most severely disabled, covers most individuals with ASD/PDD.

If the employment outcomes at this point were good, it would be hard to argue for changes in the school preparation of individuals with ASD/PDD for work. We submit, and these statistics are offered as support, that the employment situation would have to be deemed disappointing by both client and government standards. In order for this employment situation to improve in Ohio, people with ASD/PDD must be better identified and the school-to-work transition approach significantly modified.

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 40/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.

Employment & Earnings of People with Disabilities

- 1) In 1995, according to "Disability Statistics" from the U.S. Bureau of the Census:
 - (a) For persons ages 16-64 with ongoing disabilities that reduce the potential to work (16.9 million)
 - Only 27.8% were employed (4.7 million)
 - 72.2% were unemployed (12.2 million)
 - 30.0% were living in poverty (5.1 million)
 - (b) For persons ages 16-64 with severe ongoing disabilities, including those with autism (10.4 million of the 16.9 million)
 - Only 7.5% were employed (0.8 million)
 - 92.5% were unemployed (9.6 million)
 - 38.3% were living in poverty (4.0 million)
- 2) Even for people with disabilities who have jobs, income level may be below national averages due to a combination of lower hourly wages and reduced working hours.
 - People with ongoing disabilities that reduce the potential to work earn only 63.6% as much as people without disabilities.
 - When the comparison is limited to those working full time, people with ongoing disabilities that reduce the potential to work earn only 85.3% as much as people without disabilities.
 - Even so, those who work full time cannot make ends meet. 10.3% of full time workers with an ongoing disability fell below the poverty line.

3) Based on 1995 VR (vocational rehabilitation) closures, the employment outlook was not improving. In that year, according to national VR closures records for supported employment.

	<u>For all closures</u>	<u>For those with autism</u>
# of people	18,142 (100%)	127 (0.7%)
Mean weekly earnings at closure	\$114.00	\$101.62
Mean hourly earnings at closure	\$4.62	\$4.47
% of closure at/above minimum wage	72.8%	73.1%
Mean hours worked at closure	24.3	22.9
Mean VR case service \$'s	\$4,691	\$5,604

- 4) One reason for reduced wages may be a lack of skills and education. For example, in 1995: Only 66.7% of those with ongoing disabilities that reduce their potential to work had graduated from high school

Trends of Concern

The Government rolls of people receiving SSI or SSDI also show trends that should concern stakeholders.

- 1) In 1993, according to the Disability Statistic Center:
 - 6.7 million working age people received either SSDI or SSI checks, a 50% increase since 1982.
 - The largest increase has been among young adults with 43% more people under age 30 receiving SSDI benefits in 1993 than in 1989.
- 2) In the 1999 December Quarterly Report from the Social Security Division, the disappointing earnings trends continue.
 - Total SSI Beneficiaries of working age 3,758,427
 - Total SSI Beneficiaries at SGA**or above 103,608 (2.8%)

**Substantial Gainful Activity, in 1999 was \$700/month
- 3) The National and State Rehabilitation Services Commissions are beginning to awaken and react to these outcomes.
 - The US Department of Education has issued new VR rules that would redefine “employment outcome” to include only those outcomes in which an individual with a disability (including those with ASD/PDD) works in an integrated setting. Sheltered Employment is no longer considered a positive outcome. *These regulatory changes under Title I of the Rehabilitation Act are strongly supported by most national boards of organizations supporting people with disabilities, including the Association for Persons in Supported Employment (APSE).*

Underrepresentation

People with ASD/PDD are underrepresented in Ohio schools making their community employment more difficult due to the unique employment preparation needs.

The Ohio percentage (based on estimated resident population) of individuals with ASD/PDD ages Birth-21 served under IDEA during 1997-98 was only 28.5% of the national average (0.02% vs. 0.07%) Ohio VR closures for people with ASD/PDD are consistent with the 18-21 age group coming out of school.

- In FY '99, there were 23 closures (17 with ASD/PDD as the primary disability and the others with secondary).
- In FY '00 through months, there were 21 closures (18 with ASD/PDD as the primary disability).

Implications

The implications for the school and medical communities are clear.

- a) There needs to be better identification at an early age of individuals with ASD/PDD in Ohio.
- b) Schools must begin the employment focus at the earliest stages of special education and have that be reflected by the development of vocational skills and an employment outcome emphasis.
- c) Schools must insure parent/guardian/care givers/educators-administrators/adult service providers agencies have ongoing training in the process of vocational transition from school to work.
- d) Schools/VR agencies/Social Security Administration must assist families in the understanding and utilization of work incentives such as, but not limited to, PASS/IRWE/Individual Earned Income Exclusion.
- e) Schools and others will need to recognize that successful ongoing retention of a job in the community particularly for people with ASD/PDD, will require ongoing supports, not the typical "time limited" ones.
- f) Schools and others will need to realize that the school-to-work transition time for people with ASD/PDD is long.
- g) The school-to-work transition planning process should begin no later than age fourteen and 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) Future school special education programs will be evaluated on the effectiveness of individual outcomes (employment) in terms of:
 - Hours worked per week in the community (not sheltered setting)
 - Average hourly earnings
 - Monthly earnings versus the SGA (Substantial Gainful Activity level)
 - 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 will need 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) Schools will need to ensure the IEP team concept is comprehensive to include these other groups at appropriate times.
- k) Schools must recognize that individuals with ASD/PDD will require particular help with, but not limited to:
 - Behavior support and self management of behavior
 - Socialization skills
 - Communication skills
 - Ongoing supports to reflect the individual needs

VI. CHOOSING TREATMENT OPTIONS

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

- What characteristic behaviors of ASD/PDD 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/Caregivers to Ponder when Considering Participation in a New Intervention and/or Program:

- Does the program/therapy and anticipated outcomes meet the unique strengths/challenges/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/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?

VII. OHIO'S SYSTEM OF SERVICES FOR INDIVIDUALS WITH AUTISM SPECTRUM DISORDER/PERVASIVE DEVELOPMENTAL DISORDER AGES BIRTH THROUGH FIVE AND THEIR FAMILIES

Early Intervention - Birth Through Two

In Ohio, birth to three programs (Early Intervention Programs), Welcome Home, Ohio Early Start, and Early Intervention have been consolidated into the **HELP ME GROW** program. The Help Me Grow system in each county is directed by the **FAMILY AND CHILDREN FIRST COUNCIL**, a collaborative of child and family serving agencies, families, and other community providers and organizations, which plans and coordinates services to children birth through twenty one years.

HELP ME GROW promotes the well-being of young children through home-based specialized services and public awareness, with a special emphasis on early intervention and prevention. **HELP ME GROW** provides prenatal services and newborn home visits along with information about child development. The program helps families with young children connect with resources they need. The program provides service coordination and ongoing specialized services to families of children (ages birth to three) with disabilities.

When a child is identified with a developmental delay, the necessary early intervention services are identified for each child and family through the development of an **INDIVIDUAL FAMILY SERVICE PLAN (IFSP)**. The **IFSP** is a family-directed document, which includes goals that support the development of their child. Early Intervention services are then provided in the home, an early childhood center by County Boards of MR/DD, or other site in accordance with mandates of the Ohio Revised Code, Chapter 5126, through an Ohio Department of MR/DD EI Rule, and through policies based on the federal EI legislation, which are developed by the Ohio Department of Health. Such services include child development and family support activities provided by certified EI Specialists and therapies provided by licensed professionals such as speech, physical and occupational therapists. The focus of county board EI services and supports is to help the family meet the unique needs of their child and to work collaboratively with other providers within the statewide Help Me Grow system.

For More information and County Contacts:

Ohio Department of Health- Help Me Grow www.ohiohelpmegrow.org

Ohio Department of MR/DD- <http://odmrdd.state.oh.us/CitizensDoc/ChildrenUnder2.htm>

Preschool Special Education - Three through Five

In accordance with state law, the State Department of Education is responsible for making available educational services to preschool children with disabilities ages three to compulsory schoolage. Once it has been determined that the child has a suspected disability, the school district is responsible for completing a multi-factored evaluation (MFE). 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.

Following Program Standards of the Ohio Department of Education, local county boards of MRDD provide preschool services and family support services for some children three through five as one placement option for families. Learning opportunities are provided which are based on an (IEP). They are designed to address deficits and enhance creativity, expand problem solving strategies, challenge gross and fine motor skills, broaden social experiences, expand communication and play skills, increase independence, and build self-confidence. Services may be delivered in the home, in a center, or a combination of home/center. Classroom options range from self-contained to an inclusive setting, where preschoolers with special needs experience learning with their typically-developing peers of the same age.

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

When families wish to pursue a diagnosis, collaboration between medical services and service providers is an important part of this process. In a situation where the IFSP or IEP team determines that pursuing a diagnosis is appropriate, then the evaluation may be included as a birth through five service in either document. Programs are responsible to provide this diagnostic service as part of their comprehensive services. The diagnosis may be made either by licensed physicians or psychologists. Regardless of the area of specialty, an accurate diagnosis requires that the person have training and experience in the area of ASD/PDD.

VIII. 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.

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).

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.

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 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. These features, therefore, 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 ASD/PDD to certain frequencies of sound(s) that they show sensitivity (Rimland & Edelson, 1995).

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 ASD/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.

Autism Society of America (ASA): National advocacy and support organization devoted to ASD/PDD. Telephone number: 1-800-3-Autism. www.autism-society.org

Autism Society of Ohio (ASO): State Chapter of ASA. Info Line telephone number: (330) 376-0211. www.autismohio.org

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, 1993).

Autism: See section on Definition of Autism.

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 vary greatly depending on developmental level and chronological age of the individual. (see Appendices for DSM-IV 299.00 for diagnostic criteria)

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

Bureau of Children with Medical Handicaps (BCMh): A bureau within the Ohio Department of Health which assists families of children with special health care needs in identifying and receiving medical services.

Bureau of Disability Determination (BDD): A bureau within the Ohio Rehabilitation Services Commission which provides the determination of eligibility for services.

Bureau of Services for the Visually Impaired (BSVI): A bureau within the Ohio Rehabilitation Services Commission which provides vocational rehabilitation services to eligible consumers whose primary or secondary impairment is legal blindness or other visual impairment.

Bureau of Vocational Rehabilitation (BVR): A bureau within the Ohio Rehabilitation Services Commission which provides Vocational Rehabilitation services to eligible consumers whose primary/secondary impairment is physical, mental, and/or psychological.

Bureau of Early Intervention Services (BEIS): A bureau within the Ohio Department of Health, which administers programs and funding for identification and interventions for children with special needs.

Childhood Autism Rating Scale (CARS): A diagnostic instrument for ASD/PDD. It assesses the individual within 14 areas and a general impression of ASD/PDD, and provides a score based on a rating scale for each section. It is the best validated of the rating scales. A score at or less than 29 suggests the absence of significant features consistent with autism, while scores of 30-36 are defined as mild-moderate autism and 37-60 are severe autism. The CARS is a useful tool in diagnosing ASD/PDD but cannot be used in isolation and should not be used to measure the effectiveness of intervention.

County Collaborative Group (CCG): A local community planning and decision making body comprised of providers and families to benefit infants and toddlers (birth through two) with disabilities.

Checklist for Autism in Toddlers (CHAT): A screening instrument designed to identify at-risk children as early as eighteen months.

Developmental Disability (DD): A term used to describe a severe, chronic disability that is characterized by all of the following:

- a. Attributable to a mental or physical impairment or a combination of mental and physical impairments, other than a mental or physical impairment solely caused by mental illness
- b. Manifested before the age of 22
- c. Likely to continue indefinitely
- d. Results in one of the following:
 - In the case of a person under age three, at least one developmental delay or an established risk
 - In the case of a person at least three but under age six, at least two developmental delays or an established risk
 - In the case of a person age six or older, a substantial functional limitation in at least three of the following areas of major life activity, as appropriate for this age: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and if the person is at least age 16, capacity for economic self-sufficiency
- e. It causes the person to need a combination and sequence of special, interdisciplinary, or other type of care, treatment, or provision of services for an extended period of time that is individually planned and coordinated for the person

Diagnostic and Statistical Manual for Mental Disorders, 4th Edition (**DSM-IV**) - American Psychiatric Association, 1994 (see Appendices for Diagnostic Criteria for 299.00 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 trial 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.

Ecological assessment: Assessments that look at individual needs and interests in all current and in some cases, future environments.

Employment Networks (EN): An employment network of providers participating in the Social Security Administration’s Ticket to Work Program (being implemented 1/01 to 1/04). 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.

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.

(Ohio) Family and Children First Initiative (FCF): A Human Services policy initiative begun in 1991 by then Ohio Governor George V. Voinovich to expand needs services and supports to young children and their families in Ohio while streamlining state government and reducing bureaucracy. Each county has an FCF Council.

Free and Appropriate Public Education (FAPE): Special education and related services that 1) 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 105-17, 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.

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.

Individualized Education Program (IEP): A written statement for each child with a disability that is developed and reviewed in accordance with PL 105-17 (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 (see appendices).

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 Coach/Job Trainer: In supportive employment, generally a paraprofessional who provides on-site job training and supports to a worker with a disability. Sometimes used interchangeably with employment specialist.

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.

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.

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, 1993).

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

Multifactorial Evaluation (MFE): An evaluation conducted by a multidisciplinary team in more than one area of a child's functioning so that no single procedure shall be the sole criterion for determining an appropriate educational placement.

Natural Environment: 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.

Ohio Department of Education (ODE)

Ohio Department of Health (ODH)

Ohio Department of Human Services (ODHS)

Ohio Department of Mental Retardation and Developmental Disabilities (ODMRDD)

Ohio Resource Center for Low Incidence and Severe Disabilities (ORCLISH)

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 Disorder
- Rett Syndrome
- Childhood Disintegrative Disorder
- Pervasive Developmental Disorder-Not Otherwise Specified

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. (*See Appendices Diagnostic Criteria for 299.00 Autistic Disorder*)

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 would make them self sufficient (e.g., college fund). A person who is eligible for 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-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 the unmarried adult child of a wage earner who is disabled, retired, or deceased.

Special Education Regional Resource Center (SERRC): A statewide mechanism designed to develop and implement services and priorities in keeping with the Individuals with Disabilities Education Act (IDEA) to fulfill a critical role in providing timely and specialized assistance to parents and school personnel. There are sixteen SERRCs in the State of Ohio.

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

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

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: The purposeful, organized process of helping children who are at risk or have developmental disabilities move from one program to the next (Coleman, 1993).

Transition: 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 Inventory: An inventory approach that focuses on individual skill 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 toward graduation.

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CURRICULUMS

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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
Phone: (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
Phone: (212) 273-6517 fax: (212) 629-4113

ASSISTIVE TECHNOLOGY

Wisconsin Assistive Technology Integration Project, Penny Reed, Director Assessing Students' Needs for Assistive Technology (ASNAT), www.wati.org, assistive technology tools.

AT Tools and Strategies Assessment Kit for Students with Autism Spectrum Disorder (ASD), The Wisconsin Assistive Technology Initiative (www.wati.org)

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 , PH 410-312-3800 • FAX 410-312-3868

Community Transition

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Virginia Commonwealth University, Rehabilitation Research & Training Center on Workplace Supports. (Phone 804-828-1851) email <http://www.worksupport.com>

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Internet

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

Autism Society of America www.autism-society.org

Autism Society of Ohio www.autismohio.org

AUTISM ORGANIZATIONS

Asperger Syndrome Coalition of the US www.asperger.org

Autism National Committee www.autcom.org

Autism Network International www.ani.ac

FEAT (Families for Early Autism Treatment) www.feat.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 Research Institute www.autism.com/ari

CAN (Cure Autism Now) www.canfoundation.org

Center for the Study of Autism www.autism.org

NAAR (National Alliance for Autism Research) www.naar.org

BOOKSTORES / VIDEOS

Autism Asperger Publishing Company www.asperger.net/bookstore.htm

Autism Related Books www.autism-resources.com/books.html

Autism Society of America Bookstore www.autism-society.org/site/PageServer?pagename=bookstore

Autism Web Bookstore www.autismweb.com/books.htm

Future Horizons www.futurehorizons-autism.com

Jessica Kingsley Publishers www.jkp.com

Michigan ASA www.autism-mi.org

North Carolina ASA http://secure.appcomm.net/Merchant2/merchant.mv?Store_Code=asnc

Phat Art 4 Autism www.phatart4.com

Stanfield Publishing, Specialists in Special Education www.stanfield.com

Taconic Resources for Independence, Inc. www.taconicresources.net/books/bk4.shtml

FEDERAL AGENCIES

Center for Disease Control and Prevention: Autism Information Center www.cdc.gov/ncbddd/dd/ddautism.htm

Congressional Information www.congress.org

Office of Special Education Programs (OSEP) www.ed.gov/offices/OCERS/OSEP

National Institute of Health www.nih.gov

US Department of Education www.ed.gov

US House of Representatives www.house.gov

US Senate www.senate.gov

OTHER DISABILITIES ORGANIZATIONS

American Association of People with Disabilities www.aapd.com
ARC of Ohio: www.thearcofohio.org
ARC of the United States Home Page, www.thearc.org
Attention Deficit Disorder www.chadd.org
Council for Exceptional Children - Ohio www.cec-ohio.org
Easter Seals Northeast Ohio www.eastersealsneo.org
Family Support Collaborative www.olrs.oh.gov/fsc
Learning Disabilities Association www.LDOnLine.org
Mental Health NAMI Ohio www.namiohio.org
National Info Center for Children and Youth with Disabilities (NICHCY) www.nichcy.org
National Institute for People with Disabilities, www.yai.org
National Organization on Disabilities www.nod.org
National Parent Network on Disabilities www.npnd.org
Ohio Coalition for the Education of Disabilities www.ocech.org
Ohio Developmental Disabilities Council www.ddc.ohio.gov
Ohio Family and Children First www.ohiofcf.org
Ohio Legal Rights www.olrs.oh.gov
Ohio Speech and Hearing www.ohioslha.org
Technical Assistance Alliance for Parent Centers - The Alliance www.taalliance.org
The Association for Persons with Severe Handicaps (TASH) www.tash.org
Tourette Syndrome www.tsaohio.org

SPECIAL EDUCATION

Ohio Resource Center for Low Incidence and Severely Handicapped: www.orclish.org
Special Education Regional Resource Centers (SERRCs) There are 16:
Northwest Ohio www.nwoserrc.k12.oh.us
Northern Ohio www.leeca.org/northernohioserrc/index.htm
Cuyahoga www.csesc.org
East Shore www.orclish.org/serrc/eastshoreserrc.html
Northeast Ohio www.neoserrc.k12.oh.us
West Central www.wcoserrc.org
North Central www.ncoserrc.k12.oh.us
Mid-Eastern Ohio www.meoserrc.org
Lincoln Way www.lincolnway.k12.oh.us
Miami Valley www.mvserrc.esu.k12.oh.us
Central Ohio www.coserrc.org
East Central www.ecoserrc.org
Southwestern Ohio www.hccanet.org/swoserrc
Hopewell www.hopewellserrc.org
Pilasco-Ross www.scoesc.k12.oh.us/pilascoross
Southeastern Ohio www.seo-serrc.org
To verify which SERRC you should use visit: www.orclish.org/4_orclish_serrcs_ode/mappage.html
Tin Snips: A special education resource for Autism www.tinsnips.org

SPECIAL EDUCATION LAW

COPAA (Council of Parent Advocates and Attorneys) www.copaa.net

Disability Rights Activist www.drighits.org

IDEA Practices and IDEA News www.idea.practices.org

OLRS (Ohio Legal Rights Service) www.state.oh.us/olrs

Reed Martin www.reedmartin.com

Wrightslaw www.wrightslaw.com

STATE AGENCIES

Family Support Collaborative www.state.oh.us/olrs/fsc

Legislative Service Commission www.lsc.state.oh.us

Mental Health www.mh.state.oh.us

Mental Retardation <http://odmrdd.state.oh.us>

Office of the Governor www.gov.state.oh.us

Ohio Association for Person's in Supported Employment (Ohio APSE) Technical Assistance Line: 419-352-0506 x4065 (no website at this time)

Ohio Department of Education (Exceptional Children)

www.ode.state.oh.us/exceptional_children

Ohio Department of Health www.odh.state.oh.us

Ohio Department of Health -Help Me Grow www.ohiohelpmegrow.org

Ohio Department of MR/DD – EI

<http://odmrdd.state.oh.us/CitizensDoc/ChildrenUnder2.htm>

Ohio Developmental Disabilities Council www.ddc.ohio.gov

Ohio General Assembly www.legislature.state.oh.us

OLRS (Ohio Legal Rights Service) www.state.oh.us/olrs

Ohio Resource Center for Low Incidence and Severely Handicapped www.orclish.org

Special Education Regional Resource Centers (SERRCs) There are 16:

Northwest Ohio www.nwoserrc.k12.oh.us

Northern Ohio www.leeca.org/northernohioserrc/index.htm

Cuyahoga www.csesc.org

East Shore www.orclish.org/serrc/eastshoreserrc.html

Northeast Ohio www.neoserrc.k12.oh.us

West Central www.wcoserrc.org

North Central www.ncoserrc.k12.oh.us

Mid-Eastern Ohio www.meoserrc.org

Lincoln Way www.lincolnway.k12.oh.us

Miami Valley www.mvserrc.esu.k12.oh.us

Central Ohio www.coserrc.org

East Central www.ecoserrc.org

Southwestern Ohio www.hccanet.org/swoserrc

Hopewell www.hopewellserrc.org

Pilasco-Ross www.scoesc.k12.oh.us/pilascoross

Southeastern Ohio www.seo-serrc.org

To verify which SERRC you should use visit: www.orclish.org/4_orclish_serrcs_ode/mappage.html

State of Ohio www.ohio.gov

Vocational Rehabilitation www.state.oh.us/rsc

TRANSITION

Self Employment and Social Security Work Incentives for Person's with Disabilities (Consulting and Training on Employment and Transition to Work) www.griffinhammis.com

Social Security Administration Grant Supported Benefits Planning Assistance and Outreach Program
www.ssa.gov/work/ServiceProviders/BPAO/Directory.htm