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To: Local Directors of Special Education
Local Preschool Special Education Coordinators
Local Infants and Toddlers Program Directors

From: Carol Ann Baglin, Ed.D.
Assistant State Superintendent
Division of Special Education/
Early Intervention Services

Date: December 10, 2004

Re: Autism Task Force Report

The Maryland State Department of Education (MSDE), Division of Special Education/Early Intervention Services (DSE/EIS), convened an Autism Task Force in November of 1998 to address the issues and challenges related to providing services to young children with autism. Members of the Task Force included parents of children with autism, early intervention and preschool special education professionals, behavior specialists, a developmental pediatrician, and other experts in the field. For over two years, the Task Force met to review and discuss current research and service delivery options, hear from experts, and developed recommendations for service delivery in Maryland.

We are pleased to provide you with the Autism Task Force Report, *Service Delivery Recommendations for Young Children with Autism*. The Autism Task Force Report includes an overview of autism implications for learning, evaluation and assessment, the elements of an effective service delivery system, as well as recommendations for effective service delivery.

Decisions about the early intervention and special education services to be provided to children with disabilities from birth through age five are individualized and are made in partnership with parents through the Individualized Family Service Plan (IFSP) Process and the Individualized Education Program (IEP) Process. The DSE/EIS advises Local Infants and Toddlers Programs and local school systems to use the Task Force recommendations to inform the IFSP and IEP decision making for young children with autism in the context of the age and developmental levels of the child, the identified outcomes and goals on the IFSP/IEP, the complexity of the child's needs, and the child's natural or least restrictive environment.

There is a positive correlation between the amount of intervention and improved outcomes for children with autism. While it is not required that all young children with autism receive the specific amounts of direct service recommended, an IFSP or IEP developed for a young child with autism must include appropriate types and adequate levels of service to meet the child's identified developmental and educational needs identified within IFSP/IEP. Best practice in

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early intervention also suggests that providing direct service to a child under the age of three includes working with the family to support the child's development.

We thank the Task Force members for their hard work and commitment to improving outcomes for young children with autism. If you have comments or questions related to the Autism Task Force Report, please put them in writing to the attention of Deborah Metzger or email at dmetzger@msde.state.md.us. This information will be used to plan future technical assistance activities.

CAB:aw
Attachment

c: Local School Superintendents
Branch Chiefs/Section Chiefs



Autism Task Force Report

Service Delivery Recommendations for Young Children with Autism

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AUTISM TASK FORCE REPORT

SERVICE DELIVERY RECOMMENDATIONS FOR YOUNG CHILDREN WITH AUTISM

Maryland State Department of Education
Division of Special Education/Early Intervention Services

EXECUTIVE SUMMARY

During the past decade, the number of children in Maryland identified as having autism has increased by 350%, from 999 children in 1994 to 3488 in 2002. It should be noted that these figures do not include children birth to three years of age who receive early intervention services or a subset of children, ages three through five, who receive preschool special education services and are currently “identified” as developmentally delayed. In addition to an increase in the number of children identified as having autism, a significant number of new theories, possible causes, and potential “cures” have emerged. Parental demands for the provision of specific approaches and methodologies as well as increased hours of services have taxed the capacity of early intervention systems and local school systems to meet these demands. In an effort to support families and school systems, the Maryland State Department of Education, Division of Special Education/Early Intervention Services created the Autism Task Force to address these concerns.

The Task Force was “charged” to:

1. Determine the existing methodologies, medications, and models for the delivery of services to infants, toddlers, and preschoolers with the diagnosis of autism, or collectively, pervasive developmental disorders;
2. Clarify the issues that impact the effective delivery of early intervention and preschool special education services to children with autism and their families;
3. Identify the funding sources and allocations which are available and may be needed to provide services; and
4. Propose recommendations for a statewide policy to ensure the delivery of early intervention and preschool special education services to children with autism and their families.

The Task Force, comprised of parents of children with autism, early intervention and preschool special education professionals, a developmental pediatrician, diagnosticians, behavior specialists, and other experts in the field of autism, met over a two year period. Many hours were spent reviewing, discussing, and analyzing methodologies, funding stream options, and examining the ways in which the significant increase of children with autism was impacting the capacity of early intervention and preschool special education programs to deliver services. The consensus of the Task Force was:

- the increase in the identification of children with autism was genuine

- no one particular methodology or treatment would benefit all children;
- significant additional funding was needed to address identified need; and
- there was a positive correlation between the amount of direct intervention and improved outcomes for children with autism.

The Task Force concurred that for programs and services to be designated as a “best practice” for young children with autism, they must include:

- a continuum of services based on the needs of each child/family;
- ongoing support to families including:
 - daily/weekly communication with early intervention/preschool staff,
 - parent training and assistance in developing home programs,
 - referrals to parent support groups and family support services, and
 - an increased focus on the Individualized Family Service Plan (IFSP)/Individualized Education Program (IEP) process and document;
- a statewide plan for the provision of training opportunities for professional and paraprofessional providers;
- evaluations that consider educational, developmental, and medical issues; and
- an appropriate number of hours of direct intervention services provided.

Specifically, the Task Force recommended that, after considering the focus of the desired outcomes, the age and developmental level of the child, developmentally appropriate practices, the needs of the family, the intensity and complexity of the child’s needs, and the natural or least restrictive environment, the following amount of direct services should be provided to children with autism spectrum disorders:

- children between the ages of birth and three years old should receive a minimum of 10-20 hours per week of direct intervention services; and
- children between the ages of three and five years old should receive a minimum of 15-30 hours per week of direct intervention services.

These recommendations are designed to assist local early intervention systems, local school systems, and families as they determine appropriate programs for young children with autism spectrum disorders and their families.

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**This document can be downloaded from
www.marylandpublicschools.org**

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PURPOSE AND SCOPE

In the past decade, the number of children identified with characteristics of autism has increased significantly in nearly every jurisdiction in Maryland. This increase has been documented not only in Maryland, but throughout the United States. The impact of these increasing numbers of children on early intervention and education systems is significant.

Maryland Students with Autism Ages 3-21

Jurisdiction	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003
Allegany	0	0	0	1	1	3	4	5	8	12	16
Anne Arundel	33	49	78	132	187	206	238	268	316	397	468
Baltimore City	85	106	167	227	280	323	355	374	397	421	443*
Baltimore	54	83	121	163	218	306	342	382	442	557	637
Calvert	0	1	3	7	13	17	25	39	48	79	108
Caroline	0	0	5	6	10	11	16	17	18	16	20
Carroll	8	12	18	25	26	28	31	38	51	70	92
Cecil	1	2	1	5	9	9	11	19	36	43	47
Charles	4	7	5	7	10	14	20	30	37	50	71
Dorchester	0	1	3	3	2	4	1	3	6	8	9
Frederick	3	8	26	50	75	91	122	131	156	197	235
Garrett	0	0	0	1	1	1	0	0	0	0	3
Harford	7	16	13	18	19	34	46	57	63	100	127
Howard	10	38	64	106	129	169	191	236	291	332	361
Kent	0	0	0	0	1	3	1	2	4	7	8
Montgomery	30	37	74	65	65	82	128	266	409	535	684
Prince George's	19	49	90	134	175	209	250	326	404	482	525
Queen Anne's	2	2	3	4	6	8	10	7	7	13	18
St. Mary's	1	1	3	8	7	13	19	15	27	32	53
Somerset	0	0	1	4	4	5	6	6	6	9	11
Talbot	0	0	1	3	3	4	6	7	8	15	13
Washington	3	6	9	12	17	27	29	35	39	53	64
Wicomico	0	2	10	15	21	22	26	32	39	46	52
Worcester	0	2	2	3	3	5	9	9	11	14	19
Total	260	422	697	999	1,282	1,594	1,886	2,304	2,823	3,488	4,084

*Includes Edison Schools Source: MSDE Special Education Census Reports 1993-2003

Although the reasons for the increase are uncertain, there appear to be a variety of factors contributing to the increase in children between the ages of birth and five identified as having characteristics of autism. The Maryland State Department of Education, Division of Special Education/Early Intervention Services created the Autism Task Force in response to the increasing number of young children with autism in Maryland, their families, and the professionals who serve them.

Charge to the Autism Task Force

The purpose of the Task Force was to address the following four-part “charge.”

- (1) Determine the existing methodology, medication, and models for the delivery of services to infants and toddlers and preschoolers with the diagnosis of autism, or collectively, pervasive developmental disorders (PDD);
- (2) Clarify the issues which impact on the effective delivery of early intervention and preschool special education services to children with autism and their families;
- (3) Identify the funding sources and allocations, which are available and may be needed to provide services;
- (4) Propose recommendations for a statewide policy to ensure the delivery of early intervention and preschool special education services to children with autism and their families.

The Task Force recognizes that programming for children with autism is a process that changes as the child ages and new techniques are proven successful. This process begins with the provision of early intervention and preschool special education services (birth to five years).

As the prevalence of autism has increased, so too has the number of available treatments and methods of intervention. Recent research in the areas of diagnosis, etiology, epidemiology, and early intervention has advanced our understanding of autism. These advances can be incorporated into the day-to-day care and education of children with autism, support for their family members, and training for the staff that provide their educational and therapeutic interventions. As the rapid expansion of knowledge shapes our understanding of the diagnosis and provision of intervention and education to children with autism, the goal of incorporating research findings into early intervention and special education services poses a challenge to public and private service-providing groups, as well as to families. The goal, however, remains the same – to identify and incorporate research-based practices into the fabric of our policies, procedures, and professional development. This report provides a brief overview of autism and offers suggestions regarding effective practices that each local Infants and Toddlers Program and local school system should implement for children documented as having autism spectrum disorders.

THE NATURE OF AUTISM SPECTRUM DISORDERS

Autism is a developmental disability that typically appears during the first three years of life. The result of a neurological disorder that affects functioning of the brain, autism and its associated behaviors may occur in more than 25 of every 10,000 people. This represents more than one in 500 births. It is conservatively estimated that nearly 500,000 individuals in the United States. Based on a rate of 25 per 10,000, this would suggest that over 7,000 individuals in Maryland have some form of autism.

Autism interferes with the normal development of the brain in the areas of reasoning, social interaction, and communication skills. Children and adults with autism typically have difficulties with verbal and non-verbal communication, social interactions, and leisure or play activities. The disorder makes it difficult for them to communicate with others and relate to the outside world. They may exhibit repeated body movements (hand flapping, rocking, etc.), have unusual responses to people or attachments to objects, and resist changes in routines. In some cases, aggressive and/or self-injurious behavior may occur.

Although we don't know why, autism is four to five times more prevalent in boys than girls, and knows no racial, ethnic, or social boundaries. Family income, lifestyle, and level of education do not affect the chance of occurrence.

Autism is often referred to as a spectrum disorder, meaning that the symptoms and characteristics of autism can present themselves in a wide variety of combinations, from mild to severe. Although autism is defined by a certain set of behaviors, children can exhibit any combination of these behaviors with varying degrees of severity. Two children with a diagnosis of autism can act very differently from one another.

A diagnosis of autism is based on the standards set forth in a diagnostic handbook, the "Diagnostic and Statistical Manual", now in its fourth edition (DSM, 1994; see Appendix A). Several autism-related disorders are grouped under the broad heading "Pervasive Developmental Disorder" or PDD. They include autism, PDD-NOS (Pervasive Developmental Disorder-Not Otherwise Specified), and Asperger's Disorder, as well as the less frequently occurring, Rett's Syndrome and Childhood Disintegrative Disorder. PDD-NOS and Asperger's disorder are diagnoses often used by professionals to describe individuals who manifest some, but not all, of the characteristics associated with classic autism.

The presence of autism can be difficult to diagnose. Each diagnosis relies on perceptive observations of the child, ideally across several settings (home, school, clinic, etc.), by professionals with a knowledge of autism. It is important to understand that whatever the type of autism diagnosis, children with an autism spectrum disorder are likely to benefit from similar approaches to education and treatment.

The Causes of Autism

Across the country, states, local school systems, and early intervention programs are reporting significant increases in the number of children with autism in their jurisdictions. The improvement in diagnostic criteria and tools has supported the diagnosis of children who were previously undiagnosed or were diagnosed with other disabilities, including those children falling at either end of the autism continuum: including those with severe to profound mental retardation, as well as those with normal

to high intellectual abilities. Even with improved diagnostic tools, however, there appears to be a real increase in the number of children with autism spectrum disorders. Many researchers and research institutes, including the Centers for Disease Control and Prevention (CDC), are researching the various factors that may play a role in the increasing rate of autism. The CDC has recently implemented a project that will set up a system for accurately estimating the prevalence of autism in the United States and tracking it over time. To begin with, autism and autism spectrum disorder prevalence will be estimated each year using the same common, standardized, scientific methodology in six different regions of the country. One of these six regions is comprised of Delaware and northeastern Maryland, including Baltimore City and Baltimore, Carroll, Cecil, Harford, and Howard Counties. The Maryland-Delaware site has the support of the Maryland State Department of Education and Department of Health and Mental Hygiene and is housed at the Johns Hopkins Bloomberg School of Public Health.

Medical researchers are exploring different explanations for the various forms of autism. Although no single cause of autism is known, current research links autism to biological or neurological differences in the brain. Scans, such as the MRI (Magnetic Resonance Imaging) and PET (Positron Emission Tomography), show abnormalities in the structure of the brain, with significant differences within the cerebellum, including the size and number of Purkinje cells. In some families, there appears to be a pattern of autism or related disabilities. This suggests a genetic basis to the disorder, although no one gene has been directly linked to autism. In all likelihood, research will show that several genes (and perhaps environmental factors) are involved.

Research suggests that autism is a brain-based disorder, apparently of prenatal origin. The age at which symptoms of autism manifest themselves is not yet known, but may be as early as infancy. For younger siblings of children with autism, the recurrence risk of autism has been estimated as between five and nine percent. Research into the genetic basis of autism is being conducted at a variety of levels. It is hoped that identification of the responsible genes will bring a broader understanding of the impact on brain development and function. This understanding may result in more effective treatments for individuals with autism.

Implications for Learning

Advances in neuropsychological research have assisted in the accurate diagnosis, skill assessment, and development of effective intervention strategies. This research, while addressing individual children's needs, also presents a strength-based model of children's abilities that can be applied to early intervention and education programming.

For many children with autism, sustained attention and visually-based reasoning skills often exceed the ability to shift attention and engage in verbal reasoning tasks. Some recent findings suggest that executive dysfunction (difficulty with goal-orientation, planning, self-monitoring, etc.) is characteristic of children with autism, and that this domain of functioning does not improve in children with autism as quickly as it does in children with other developmental disabilities.

The difficulty that most children with autism have in imitation is related to executive dysfunction. Imitation skills that involve sequences of movements and symbolic movements (such as pantomime) are often impacted. This has great implication for the child's ability to learn about others' intentions and mental states, speech, language, and social skills. It also has implications for the child's ability to learn complex fine motor skills such as writing. However, despite the imitation impairment in children with autism, these children are often able to learn to engage in imitation in highly structured contexts. Accordingly, they often quickly learn to imitate simple movements (e.g., clapping hands) in response

to discriminative stimuli such as “Do this.”. The challenge to early intervention specialists is to teach imitation in a way that will enhance the child’s learning to play, communicate, and interact with others.

An area of great challenge for children with autism is social-cognitive and social-emotional development. This challenge appears to be present in the first years of life and affects the child’s intention to:

- establish shared attention with others,
- monitor and understand others’ signals to establish shared attention,
- share positive emotion during social interactions,
- respond to others’ distress,
- read others’ expression of emotion,
- read social cues,
- make social inferences, and
- understand others’ perspective.

At times, individuals with autism have difficulty reading the internal cues of their own emotional state and appear to have different responses to emotional input. Although these social difficulties severely hamper the ability of the child with autism to establish reciprocal peer relationships, children with autism do form attachments to their family members and often desire friendships. They require assistance in learning to relate to others and the development of social skills to support their interactions within school, home, and community.

Communication and imaginative play are areas of challenge for children with autism. Many never develop a functional verbal communication system. Learning to understand language, particularly language that is non-literal (as in humor, puns), is difficult. Some children with autism develop early and extensive rote language systems. This can manifest as learning the alphabet before being able to say ten words or learning clips from videotapes that are recited in communicative or non-communicative contexts. Children with autism who are verbal may have great difficulty getting the ‘gist’ of a story or conversation. Social conversational skills (pragmatics) are always impaired, as seen in difficulty with conversational turn-taking, adjusting vocabulary, and other aspects of speech for the context (formal versus informal), and maintaining others’ topics. Frequently, such social communication difficulties lead to social isolation for the child with autism. Yet these skills can be taught and greatly improve a child’s social success.

Children with autism have many strengths to support them in the learning process and have been shown to demonstrate their highest skills in structured contexts. Everyone involved in the life of a child with autism will enhance a child’s ability to learn if they tailor the environment, address the child’s needs by providing visual guidelines, adjusting the level of linguistic complexity directed to the child, offering an appropriate communication system for the child, capitalizing on the child’s interests, and generally structuring the child’s interaction and learning contexts to meet the child’s individual needs.

EVALUATION AND ASSESSMENT

Autism is a neurological disorder affecting all major areas of a young child's functioning: communication, social interaction, and behavior. The severity of impact on a child's development varies from mild to severe. Some children may have communication skills in the average range, but have severe disabilities in the areas of social interaction and behavior. Some children may be nonverbal, have difficulty in relating to people, and have significant behavioral challenges. There are several defining characteristics of autism:

1. Severe delays in development of language/communication skills.
2. Severe delays in development of social interaction and play skills.
3. Behavioral issues such as repeated body movements (hand flapping, rocking, etc.) and including repetitive patterns of behavior and interests; unusual responses to people or attachments to objects; resisting any changes in routine; or injurious behavior.
4. Onset prior to age three.

In this document, the term "autism" refers to all possible categories under Autism Spectrum Disorder listed in the Diagnostic and Statistical Manual IV (DSM, 1994). The DSM-IV lists diagnostic criteria for Pervasive Developmental Disorders including, Autistic Disorder, Rett's Disorder, Childhood Disintegrative Disorder, Asperger's Disorder, and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) and can be found in Appendix A of this document.

Historically, children could not be reliably diagnosed with autism until after age three. Recent research demonstrates, however, that a very young child can be identified as having autism and a number of key symptoms of autism can be present as early as age 18 months. Studies show that autism can be reliably identified by an experienced clinician when a child is between the ages of 24 and 30 months (California Department of Developmental Services, 2002). Research clearly demonstrates the importance of early intervention in order for children to have the best developmental, behavioral, and adaptive outcomes, so early diagnosis and treatment are critical. It is essential, however, that only individuals trained and experienced with children with autism make a diagnosis. State licensure in a medical or mental health field is required to render a diagnosis of autism (ie. psychologists, pediatricians, etc.).

Identification

Identification frequently begins with parents, caregivers, and professionals noticing a speech delay with a young child. A developmental evaluation may identify delays in several other areas. There are several screening tools that can be used by early childhood professionals to determine whether further assessment and evaluation should be conducted. (See Appendix C for a list of assessment tools.)

If family members and professionals suspect that the child's developmental delays may fall within the Autism Spectrum Disorder then a medical and/or psychological evaluation should be conducted to ascertain the nature and severity of the disorder and to rule out other possible disorders which may be affecting the child's development. Further evaluation and assessment should only be conducted by professionals who have specialized training and knowledge of Autism Spectrum Disorders.

Diagnostic evaluations should:

- Elicit, value, and address parental concerns,
- Be undertaken by a multidisciplinary team,
- Review the child's developmental history,
- Include a direct behavior observation,
- Assess cognitive functioning, and
- Evaluate adaptive functioning in the areas of communication, socialization, fine and gross motor development, self help/daily living skills, and social-emotional functioning. (California Department of Developmental Services, 2002).

Families should be referred to their pediatrician to obtain a medical evaluation to rule out associated medical conditions. There are no specific medical tests that can confirm the diagnosis of autism. Autism is diagnosed by trained professionals who use highly structured and systematic observation, and the prognosis for any given child is uncertain. Some, but not all children, may derive some benefit from various biomedical interventions. Intervention services that address the developmental domains and educational needs of the child are most often recommended by medical, educational, and developmental professionals.

Evaluation and Assessment

A child under age three suspected of having autism or a developmental delay can be assessed and evaluated either at an early intervention program, the family's home, or at a childcare provider's home or center. The decision about location and time of the assessment should be made in conjunction with the family. During the assessment, Infants and Toddlers Program personnel look for detailed information about the child's strengths and needs, as well as family information that would impact on the child's development. Assessment is ongoing throughout the child and family's participation in the Infants and Toddlers program.

The assessment should:

- Detail the child's strengths and areas of need;
- Establish the child's health and developmental patterns, and profile family resources and needs within the community context;
- Determine areas in which additional information is needed; and
- Establish the foundation for development of an early intervention plan known as an Individualized Family Service Plan (IFSP) that meets the needs of the child and family.

As with diagnostic evaluations, an interdisciplinary team should undertake the assessment with input from the family with regard to their values, needs, beliefs, fears, and expectations.

Eligibility for Services

A child under three years of age who has been identified through a developmental evaluation to have deficits consistent with Autism Spectrum Disorder will qualify for early intervention services through the local Infants and Toddlers Program in the jurisdiction in which the child and family resides. No formal diagnosis is required to receive services. Depending on the extent and type of information

obtained from the evaluation and assessment, infants and toddlers may be eligible under one of three eligibility categories:

(a) Are experiencing at least a 25 percent delay, as measured and verified by appropriate diagnostic instruments and procedures, in one or more of the following developmental areas:

- (i) Cognitive development,
- (ii) Physical development, including vision and hearing,
- (iii) Communication development,
- (iv) Social or emotional development,
- (v) Adaptive development; or

(b) Manifest atypical development or behavior, which is demonstrated by abnormal quality of performance and function in one or more of the above specified developmental areas, interferes with current development, and is likely to result in subsequent delay (even when diagnostic instruments or procedures do not document a 25 percent delay); or

(c) Have a diagnosed physical or mental condition that has a high probability of resulting in developmental delay, with examples of these conditions including chromosomal abnormalities, genetic or congenital disorders, severe sensory impairments, inborn errors of metabolism, disorders reflecting disturbance of the development of the nervous system, congenital infections, disorders secondary to exposure to toxic substances, including fetal alcohol syndrome, and severe attachment disorders. (COMAR 13A.13.01.02)

A child over age three who has been screened through a local school system's Child Find Office will qualify for special education and related services if the child has a formal diagnosis of autism as defined in Maryland's regulations (COMAR 13A.05.01.03):

"Autism" means a developmental disability which:

- (a) Does not include emotional disturbance as defined in §B(20) of this regulation;
- (b) Significantly affects verbal and nonverbal communication and social interaction;
- (c) Is generally evident before three years old;
- (d) Adversely affects a student's educational performance; and
- (e) May be characterized by:
 - (i) Engagement in repetitive activities and stereotyped movements,
 - (ii) Resistance to environmental change or change in daily routines, and
 - (iii) Unusual responses to sensory experiences.

Alternatively, a child will qualify for special education and related services if the child is designated as a student with a developmental delay. Students with developmental delay must meet one of the following criteria:

- A 25 percent or greater delay in adaptive, cognitive, communicative, emotional, physical, or social development, as measured and verified by appropriate diagnostic instruments and procedures; or
- Atypical development or behavior; this can be demonstrated by abnormal quality of performance and function in one or more of the specified developmental areas, which interferes with current development and is likely to result in subsequent delay, even when diagnostic instruments and procedures do not document a 25 percent delay; or
- A diagnosed physical or mental condition as defined in COMAR 13A.13.01.02B(21)(c), which has a high probability of resulting in a developmental delay, including, but not

limited to students with sensory impairments, inborn errors of metabolism, microcephaly, fetal alcohol syndrome, epilepsy, and Down Syndrome, and other chromosomal abnormalities (COMAR 13A.05.01.03)

The categorical option of Developmental Delay may be used at local discretion for preschool and young students ages three through nine, but not beyond age nine. Whether under or over age three, family members and professionals may request a medical evaluation from a qualified professional to rule out other disorders and to more fully describe the child's current development. Dependent upon specific circumstances, this medical evaluation may or may not be paid for by the local Infants and Toddlers Program or school system. Families are advised to discuss any medical evaluation with the Individualized Family Service Plan (IFSP) or Individualized Education Program (IEP) team prior to its scheduling.

ELEMENTS OF EFFECTIVE SERVICE DELIVERY

A review of effective programs and intervention models for young children who have autism reveals several commonalities. This information is useful for public agency administrators and educators as well as parents in designing, modifying, and evaluating intervention programs. While individual programs may differ based on the unique strengths, resources, priorities, and needs of each individual child and family, an effective program should give careful consideration to including the following elements:

- Family Involvement
- Interdisciplinary Involvement
- Curriculum and Instruction
- Functional Approach to Challenging Behaviors
- Amount of Direct Intervention
- Assistive Technology
- Transition
- Professional Development
- Family Support

Family Involvement

Family involvement begins with referral, evaluation, and assessment, and continues through program development, implementation, evaluation, and transition. A collaborative relationship between parents and service providers is developed and maintained to maximize the benefits the child receives from intervention. Family involvement activities include:

- Providing education and information to family members regarding diagnosis and intervention options;
- Training of family members on selected intervention strategies and techniques; and
- Developing support activities based on each family's unique needs, that may include opportunities to network with other parents of children with autism and links with community programs and services.

Interdisciplinary Involvement

Because autism is a disorder characterized by deficits and abnormalities in multiple areas, a team approach to evaluation and assessment, program design, and service delivery is necessary. A comprehensive intervention program may include input from the following disciplines to ensure that all aspects of the disorder are addressed:

- Developmental pediatrics
- Special education
- Speech language pathology
- Psychiatry and/or psychology
- Occupational and/or physical therapy
- Public health
- Social Work (Rogers, 1999).

Curriculum and Instruction

Program design is personalized for both content and methodology. What and how the child will learn is derived from assessment information, clinical observation, and parental input. Effectively designed programs include many of the following elements:

Content

Program content emphasizes skill development in basic domains: communication and language; social tolerance, interaction and engagement; attending; imitation; motor function; concept development; and appropriate play. Goals, objectives, and outcomes are clearly addressed in the IFSP or IEP, address deficit areas, and lead to greater independence in functional and meaningful activities. Specific skill sequences are selected based on developmental stages and milestones and are hierarchical. Core skills are taught before more complex ones.

Highly Supportive Learning Environments

Highly supportive teaching and learning environments have predictability and established routines. Intervention may be provided in homes, community settings, or public sites. Skills that are established in highly structured settings are systematically generalized to other environments. Regardless of setting, the learning environment should include:

- A low staff to child ratio (1:1 or 1:2), particularly during the initial period of intervention;
- Adaptations to assist with changes in activities or routines (transitional objects, visual schedules using pictures or written words);
- Environmental design to maximize attention to relevant information and minimize confusion and distractibility;
- Repeated opportunities to learn and practice skills; and
- Opportunities to interact with typically developing peers.

Selection of Effective Instructional Strategies

Team members, including the parent, select instructional strategies, techniques, and methodologies based on the:

- Developmental level of the child;
- The child's learning style, strengths, and needs; and
- The skill or task to be taught (HCPSS, 1998).

Data-based Decision Making

IFSP outcomes and IEP goals and objectives must be written in clearly measurable terms. Efficient and effective data collection methods must be utilized consistently across environments and service providers, including caregivers, to ensure response to intervention, as well as generalization and maintenance of skills. Modifications should be made to intervention plans and teaching methods, materials, and strategies based on on-going data analysis.

Functional Approach to Challenging Behaviors

Positive behavioral supports are designed to promote behavioral change. The function of inappropriate behavior is determined through observation and analysis and the child is taught alternative appropriate behaviors to serve the same function. Proactive strategies to prevent problem behaviors may include:

- Modifying antecedent or setting events;
- Implementing consequence strategies;
- Using highly preferred materials or activities (as teaching materials, motivators, and reinforcers);
- Alternating preferred and non-preferred activities; and
- Prompting or modeling appropriate responses, with gradual prompt fading (HCPSS, 1998).

Amount of Direct Intervention

Review of research emphasizes the importance of early, intensive intervention. The number of hours of service in a home, school, or community setting is determined through the IFSP/IEP process. The amount of direct intervention is customized to meet the unique needs of the child and family. Intervention programs are designed to include direct instruction to the child and training and participation of family members and caregivers. Services are modified to meet the changing needs of the child and family.

Amount of Direct Intervention for Children of Infant and Toddler Age (Birth through Two Years)

Although intervention models for infants and toddlers who have autism will include many of the elements outlined in this section, they will also have unique features that recognize the developmental ages and stages of the younger child. The importance of the child-caregiver interaction during this period of development may necessitate increased intervention in natural settings with the caregiver as interventionist. Program design includes emphasis on attention and response to social aspects of the child's everyday activities and routines in the natural environment (Dawson and Osterling, 1997). The professional serves the role of coach in training family members to maximize initiation, engagement, and interactions.

Guidelines for the amount of direct intervention with infants and toddlers varies in accordance with different program designs. Gail McGee, researcher and director of the Walden School at Emory University, reported that for toddlers the "Hours of engaged time are key to children's learning, and more hours of engaged time is better than less." (McGee, et al, 1999). The Walden School at Emory University provides both school and home-based services for toddlers with autism and McGee emphasizes the important role of family members in implementing the child's intervention plan stating, "well prepared family members (including parents, grandparents, siblings, and others) are capable of adding substantially to the number of intervention hours that their child receives each week." (McGee, et al, 1999). Rogers (1996) states, "Children with PDD/autism appear most able to benefit when intervention is begun very early, between ages two and four, making far more progress than older children receiving the same interventions, and when interventions were intensive, including 15 or more hours per week of focused treatment with low child to adult ratios."

Amount of Direct Intervention for Children of Preschool Age (Three through Five Years)

As children enter the preschool years, treatment may be more focused on learning school-readiness behaviors and skills. Carryover of skills taught in school-based settings to the home and other community environments and addressing other non-school related deficits also remain imperative to effective programming. A review by Dawson and Osterling (1997) evaluated eight model early intervention programs for preschool children with autism. The range of school-based hours per week was from 15 to 40 with an average of 27 hours. All of the programs included a family training and participation component which added to the total hours. The researchers surmised that the actual hours of intervention were probably even greater. Dawson and Osterling report that, "Although it is not possible to conclude from these data what is a necessary and sufficient number of hours per week of school-based intervention required for a positive outcome, this information does offer an estimate of the number of school-based hours needed by young (preschool-age) children with autism."

Amount of Direct Intervention: Research Findings

In 2001, at the request of the Office for Special Education Programs (OSEP), the National Research Council (NRC) published *Educating Children with Autism*, a monograph and recommendations developed by a committee of experts. The committee's recommendations were made on the basis of empirical findings, information from selected representative programs, and reviews of findings in the general education and developmental literature. The committee noted that "it is well established that children with autism spend much less time in focused and socially directed activity when in unstructured situations than do other children, and it is therefore crucial to specify time engaged in social and focused activity as part of a program for children with autism spectrum disorders." The committee did not delineate between service levels for children under and over age three, but recommended that:

Based on a set of individualized, specialized objectives and plans that are systematically implemented, educational services should begin as soon as a child is suspected of having an autistic spectrum disorder. Taking into account the needs and strengths of an individual child and family, the child's schedule and educational environment, in and out of the classroom, should be adapted as needed in order to implement the IEP. Educational services should include a minimum of 25 hours per week, 12 months per year, in which the child is engaged in systematically planned, developmentally appropriate educational activity aimed toward identified objectives. Where this activity takes place and the content of the activity should be determined on an individual basis, depending on the characteristics of both the child and the family. (NRC, 2001).

The NRC Monograph, which represented a consensus among experts in a variety of fields including special education, clinical and developmental psychology, speech and language pathology, psychiatry, and child neurology, supports the following previous findings by academics specializing in the field of autism:

- Provide intensive services to toddlers and preschoolers. The cost of intensive (one-to-one) services for every two-, three- and four-year-old diagnosed as having autism or pervasive developmental disorder would undoubtedly be extremely high. But the current, often feeble attempts at intervention for this population are unlikely to reduce the even greater cost of maintaining a very large proportion of autistic individuals as seriously disabled throughout their lifetimes. It is cost-effective to help as many autistic children as possible become part of mainstream society early in their lives, and we need intensive

efforts to accomplish this. Not every child diagnosed as having a pervasive developmental disorder needs 30 or 40 hours a week of formal educational treatment services for an extended period of time; and some children who begin receiving intensive services at age two or three will, a year or two later, be able to learn effectively in small groups and benefit from supported participation in inclusive settings. (Cohen, 1998)

- Moreover, despite widespread recognition that in treatment of autism early is essential and more is better, the current state-of-the-art treatment in early intervention for autism is good preschool education. When children with autism enter treatment before preschool ages, they are usually provided with a diluted preschool curriculum. There is a void of information on what is most crucial to teach toddlers with (or at risk for) a diagnosis of autism, or how best to teach them. This is a critical problem, given the relatively short time frame in which early intervention must occur. In sum, it is important to know how to best lay a foundation for the growing number of effective preschool interventions. (McGee, et al, 1994)
- Many parents instinctively try harder and do more and basically add more stimulation when their child does not respond normally. With autistic children, however, just adding “more” is not enough. The special difficulties experienced by autistic children warrant a form of special education unique to their disorder. Sometimes the most severely impaired children—those for whom even the most intensive services will not make a critical difference—tend to be offered more services than children who have fewer initial impairments or who may be more ready to tolerate intensive work. In fact, children with the mildest disabilities typically are offered fewer services than more moderately impaired children because it is felt they may improve eventually on their own. To the extent that there are any real data on who should get how much service, there is reason to believe that more intensive interventions for more mildly affected children may be particularly efficacious. (Seigel, 1996)

Furthermore, the NRC monograph made the following additional recommendations for effective treatment:

- A child must receive sufficient individualized attention on a daily basis, so that individual objectives can be effectively implemented; individualized attention should include individual therapies, developmentally appropriate small group instruction, and direct one-to-one contact with teaching staff.
- Assessment of a child’s progress in meeting objectives should be used on an ongoing basis to further refine the IEP. Lack of objectively documentable progress over a three month period should be taken to indicate a need to increase intensity by lowering student/teacher ratios, increasing programming time, reformulating curricula, or providing additional training and consultation.
- To the extent that it leads to specified educational goals (e.g., peer interaction skills, independent participation in regular education), children should receive specialized instruction in settings in which ongoing interactions occur with typically developing children. (NRC, 2001).

Assistive Technology

The use of assistive technology is an important consideration in the treatment of children with autism. Parents and teachers have supported the use of both low- and high- technology tools for children with autism at each stage of the developmental process.

Low tech tools include communication systems (to augment expression, but also to provide a stable representation of input), self-organizational systems (e.g., picture schedules), learning assists (e.g., visual guides or templates to assist with the completion of a task), behavior monitoring guidance systems (e.g., timers, visual systems for indicating emotional response), and more. High tech systems are beneficial once a child has a basic conceptual system established, and in the case of communication, has demonstrated both consistent communicative intent and a basic repertoire of symbols. There are numerous options for implementing a high tech communication system, and even more options within these systems for individualizing the complexity of the language and representational system utilized (e.g., pictures, icons, letters).

Several excellent resources are now available for assisting teams in the appropriate selection of a communication system for a child, but the consultative input from an expert in assistive technology or speech-language pathologist will be needed during the system selection process and in the treatment design (and perhaps implementation) process. Regardless of whether a high or low tech communication system is selected to augment verbal communication, teams must consider the earliest possible implementation of these systems, so that children do not go for years without a communication system while the team hopes for the emergence of speech. The augmentative system will not prevent speech from emerging. Furthermore, the communication system must be utilized throughout the child's day. Teachers, service providers, aides, peers, parents, siblings, grandparents, neighbors—all must use the communication system with the child. Natural and contrived communication situations will have to be provided to encourage and maintain the child's use of the communication system.

Technology is also a critical component of the developmental process, both for teaching play skills (cause-effect toys are a good place to start), recreational skills (playing computer games), pre-academics, and academics (specialized computer games for teaching matching skills, visual-spatial skills, language comprehension, math, reading, and more). Again, the assistive technology consultant will be helpful in deciding whether such a system is appropriate, and in selecting appropriate software and hardware.

Transition

A common characteristic of children with autism is difficulty with transition to new activities or situations. The transition from the local Infants and Toddlers Programs at age three and from preschool programs to elementary programs at age five or six presents many challenges for children, families, and professionals. A key aspect of effective programs is thoughtful preparation of the child and family for transition to new programs.

Successful transitions from local Infants and Toddlers Programs to preschool services and from preschool services to elementary school programs are the result of systematic planning, thorough implementation, and follow-up activities to ensure that the child and family move to the next intervention setting with minimal disruptions in service delivery. It is important to understand that both

the child and the family are making the transition. Transition activities are designed to ensure that the child will succeed in the next program and that the family is a full partner in the decision-making process. Service providers can help guide parents in developing a repertoire of transition skills that can be applied to subsequent transitions throughout their children's lives.

For successful transitions, it is important that all key personnel and stakeholders are involved in the transition process and understand their roles. In addition to the child and parents, key personnel include the current service providers as well as future administrators and service providers. Key activities in the transition process include:

- Identifying key personnel from the current and future programs;
- Developing a transition action plan which outlines activities, events, timelines, and responsibilities;
- Recommending necessary evaluations and assessments;
- Arranging for current service providers and parents to observe programs which may be considered;
- Modifying the child's current program to be similar to the future environment;
- Visiting the future environment, if appropriate;
- Arranging for future service providers to observe the child in the current environment;
- Training future service providers, if needed;
- Scheduling necessary special education meetings and IEP reviews;
- Transferring records and other information to the receiving program; and
- Evaluating the transition process through follow-up activities. (HCPSS, 1999).

Professional Development and Support

Intervention programs designed to meet the needs of children with autism and their families include a variety of staff and parent training opportunities. Service providers and family members have the training and expertise necessary to make sound judgments regarding which types of approaches are likely to be most effective for the child and how those approaches may be combined to enhance their effectiveness. (HCPSS, 1998).

There are models of personnel preparation and training available within Maryland early intervention programs and local school systems, as well as within some universities. Program administrators should be challenged to implement effective personnel preparation and training, "beyond a single training effort, to provide a continuum of services across time." (NRC, 2001)

Gallagher and Clifford (2000) state that there are seven elements necessary to develop an infrastructure designed to train and support direct service providers (special educators, paraprofessionals, related service personnel) to work effectively with children with autism.

Elements of a Support Infrastructure

Personnel Preparation	There is need for continuous flow of qualified personnel. To that end, there needs to be a series of training programs and experiences directed at preservice and inservice needs.
Technical Assistance	Many professionals and programs run into situations related to autism that cause them to seek additional professional help. Programs of technical assistance are designed to provide consultation and short-term training to meet the needs of the requester.
Applied Research and Program Evaluation	There is a strong need to be reflective about our own performance as part of a strategy of continuous improvement. Public calls for accountability stress the importance of developing the proper tools and measuring instruments and personnel to conduct effective program evaluation.
Communication	It is important to establish a communications network so that there is continuous contact with other professionals who are working on the same or similar problems. It is a way of keeping up with the latest knowledge and practices.
Demonstration	One of the strategies that has been often used to improve program quality is to identify outstanding programs, establish them as demonstration centers, and then urge other professionals to observe and emulate what is happening in those centers or programs that could be transferred to their own program.
Data Systems	There are many important policy questions that cannot be answered without an organized data system. Questions such as, "How many children with autism are there?" or "How many teachers are needed?" can only be addressed if one has a data system to compile demographics of the individuals or programs.
Comprehensive Planning	One of the key aspects of an infrastructure is the ability to do comprehensive statewide or system-wide planning and to be able to allocate resources over time and in a systematic manner to more easily reach the goals of the program.

Source: Gallagher and Clifford (2000), in NRC, 2001.

Family Support

A diagnosis of autism begins the most profound series of changes that a family will probably ever experience. It is a journey of sadness, frustration, joy, and love, through which parents will likely experience tremendous personal growth. Receiving a diagnosis of autism can throw family members into a situation that may make their lives different from those of other families. The birth of an exceptional child into a family requires considerable adjustment on the part of family members. Families receiving a diagnosis of autism for a child will probably feel many things at once. They may feel a sense of relief that what they have been concerned about has a name; they may be frightened for their child's and family's future; they may be feeling guilt, wondering if they caused their child's autism. Existing research into how parents cope with a diagnosis of autism reveals that they each go through a process of grieving. However, instead of grieving for a child who has died, they experience the loss of an "idealized" or "hoped for" child. (Seigel, 1997).

It is clear that caring for a child with autism is difficult for families and that there is a need, not only for mandated early intervention and education services for their children, but for other supports and services to assist families in their homes and in the community. Families should be referred to their local Family Support Network and Partners for Success Centers, as well as to local parent-to-parent programs and support groups such as those run by the Autism Society of America. (See Appendix J for a listing of autism support organizations).

Families of children with autism may require additional family support services such as respite and child care, in-home behavioral training, adaptive equipment and assistive technology, social and recreation activities, and other services and supports unique to each family's needs. Families should be referred to the Developmental Disabilities Administration (DDA) Regional Office in their area or a local service provider regarding Family Support Services that are often critical services in avoiding family crises that become much more costly, both emotionally and financially. Parents should know that family support services are not an entitlement, which means they may not be available to all eligible families because of limited funding. Limited funding also means that although Family Support Services typically can't meet all of a family's needs, they can help in very significant and important ways. Family support Services are provided by local service providers with funding from the DDA. To apply for services, families should contact a local Family Support Service provider directly. For a list of agencies providing Family Support Services, call a regional DDA office (See Appendix G).

Children with autism and their families receiving medical assistance (Medicaid) may also be eligible for additional services, including in-home behavioral supports. Families should contact their Managed Care Organization's (MCO) special needs coordinator for assistance in accessing services. Children that qualify for the State's Autism Medicaid Waiver may receive additional services such as respite care, environmental modifications, and intensive individual support services. Families interested in applying for the Autism Medicaid Waiver are encouraged to call the Registry at 1(866) 417-3480.

TASK FORCE RECOMMENDATIONS: EFFECTIVE PRACTICES

A. General Considerations

An effective service delivery model for children with Autism Spectrum Disorder requires that local Infants and Toddlers and preschool education programs provide a continuum of services that are based on the individual strengths and needs of the child and family. Needs drive services, and service delivery systems must be flexible to accommodate changes based on the child's progress and specific challenges that may present as the child develops. Local Infants and Toddlers and preschool education programs must consider the effective program components cited in these guidelines as they strive to provide on-going, flexible programming to meet the individual needs of children with autism and their families.

B. Family Involvement

Throughout this document, family involvement with the early intervention and education systems has been recognized as a critical element in identifying, developing, and implementing appropriate programs and services for young children with autism. Thus, specific to family involvement, the Task Force recommends that:

1. On-going methods and schedules of communication (e.g., notebooks, data sheets, weekly phone calls, emails, etc.) between service providers and families should be discussed at IFSP/IEP meetings.
2. Intervention programs for young children with autism include both a home component and a parent training component to assist in generalization of skills.
3. Upon diagnosis of an autism spectrum disorder, the family be referred to local resources including parent support groups and family support services.
4. In developing the IFSP/IEP, the team gives full consideration to the families resources, priorities, concerns and needs, and the profound effect that autism has on the family unit.

C. Training

Of all of the elements that the Task Force discussed and investigated, it was agreed that training is the most frequently overlooked, and yet, it is the most fundamental component across all facets of programming. Thus, specific to training, the Task Force recommends that:

1. MSDE develop a statewide plan for the provision of training opportunities.
2. Training by local Infants and Toddlers programs and school systems must be available for:
 - a. paraprofessionals, including but not limited to: 1:1 aides, instructional assistants; teaching assistants, paid-parent-helpers, etc.
 - b. families (including foster and extended family members)
 - c. professionals, including but not limited to: special educators, general educators, occupational therapists, physical therapists, mental health professionals, speech and language pathologists, etc.

3. At a minimum, service providers must receive training in elements of effective service delivery. These elements include, but are not limited to:
 - a. multi-domain curriculum content
 - b. highly supportive teaching environments and generalization strategies
 - c. need for predictability and routine
 - d. functional approach to problem behaviors
 - e. transition
 - f. family involvement and support
 - g. data collection

D. Diagnosis and Assessment

In the state of Maryland, it has been noted that many families enter the early intervention or special education systems having already acquired an independent evaluation and/or diagnosis indicating that their children have Autism Spectrum Disorder. Regardless of whether or not the family receives evaluation and/or diagnostic information from within or outside of the early intervention or educational systems, the Task Force recommends that:

1. Only qualified professionals conduct the evaluation.
2. Evaluations consider educational, developmental, and medical issues.

E. Amount of Direct Services

1. When determining the amount of direct services provided (i.e. the number of hours of direct service and the staff to child ratio), to children between the ages of birth and five years old who have been diagnosed with characteristics of autism, the Task Force recommends that the following variables be considered:
 - a. the outcomes desired;
 - b. the age and developmental level of the child;
 - c. developmentally appropriate practices;
 - d. issues related to the needs of the family – resources, routines, priorities, etc.;
 - e. intensity and complexity of child’s needs;
 - f. the degree of integrated service delivery;
 - g. the flexibility of service delivery providers;
 - h. continuum of service options; and
 - i. natural environment/least restrictive environment.
2. Given the individual needs of the child, the Task Force recommends that children between the ages of birth and three years old should receive a minimum of 10*-20 hours per week of direct service intervention.
3. In most cases, children between the ages of birth and three are provided services within their home environment where the staff to child ration is likely to be 1:1.
4. Given the individual needs of the child, the task force recommends that children between the ages of three and five years old should receive a minimum of 15*-30 hours per week of direct service intervention.

5. Whether in the home or in a center-based preschool environment, the task force recommends a staff to student ratio of 1:1 or 1:2, with a goal of decreasing that ratio as the student is able to learn and participate in a small group setting.

*Members of the task force engaged in intense deliberation on the issue of hours of services in an attempt to balance the research supporting best practices documented throughout the country and the necessity for services based on the individual needs of a child with autism. It is recommended that at least 10 hours of services be a starting point for a child with autism and, as he or she can tolerate more intense services, additional hours be introduced with the goal of increasing the daily number of hours that the child is engaged in direct service intervention.

These guidelines are designed to assist local early intervention and school systems and families as they program for young children with autism spectrum disorders.

APPENDICES

- A DSM-IV Definition of Autism
- B Common Questions About Autism
- C Assessment Tools
- D Local Infants & Toddlers Offices
- E Instructional Methods
- F Day Care Resources
- G Family Support Services through the Developmental Disabilities Administration
- H Glossary of Terms
- I Parent Support Groups and Resources
- J Maryland's Autism Medicaid Waiver Fact Sheet
- K Bibliography

Appendix A
DSM-IV Criteria

The full diagnostic criteria for the pervasive developmental disorders are outlined below. As mentioned above, the diagnostic criteria for the autistic (PDD) disorders are defined by the DSM IV criteria.

I. Childhood autism

- A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):
 - 1. Qualitative impairment in social interaction, as manifested by at least two of the following:
 - a. marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction.
 - b. failure to develop peer relationships appropriate to developmental level
 - c. a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
 - d. lack of social or emotional reciprocity
 - 2. Qualitative impairments in communication as manifested by at least one of the following:
 - a. delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
 - b. in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
 - c. stereotyped and repetitive use of language or idiosyncratic language
 - d. lack of varied spontaneous make-believe play or social imitative play appropriate to developmental level
 - 3. Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities, as manifested by at least of one of the following:
 - a. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
 - b. apparently inflexible adherence to specific, nonfunctional routines or rituals
 - c. stereotyped and repetitive motor mannerisms (e.g. hand or finger flapping or twisting, or complex whole body movements)
 - d. persistent preoccupation with parts of objects

- B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.
- C. The disturbance is not better accounted for by Rett's disorder or childhood disintegrative disorder.

II. **Asperger's syndrome**

- A. Qualitative impairment in social interaction, as manifested by at least two of the following:
 - 1. marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
 - 2. failure to develop peer relationships appropriate to developmental level
 - 3. a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
 - 4. lack of social or emotional reciprocity
- B. Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities, as manifested by at least of one of the following:
 - 1. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
 - 2. apparently inflexible adherence to specific, nonfunctional routines or rituals
 - 3. stereotyped and repetitive motor mannerisms (e.g. hand or finger flapping or twisting, or complex whole body movements)
 - 4. persistent preoccupation with parts of objects
- C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.
- D. There is no clinically significant delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years).
- E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood.
- F. Criteria are not met for another specific pervasive developmental disorder or schizophrenia.

III. **Rett's disorder**

- A. All of the following:
 - 1. apparently normal prenatal and perinatal development

2. apparently normal psychomotor development through the first five months after birth
 3. normal head circumference at birth
- B. Onset of all of the following after the period of normal development:
1. deceleration of head growth between ages 5 and 48 months
 2. loss of previously acquired purposeful hand skills between ages 5 and 30 months with the subsequent development of stereotyped hand movements (e.g., handwringing or handwashing)
 3. loss of social engagement early in the course (although often social interaction develops later)
 4. appearance of poorly coordinated gait or trunk movements
 5. severely impaired expressive and receptive language development with severe psychomotor retardation

IV. **Childhood disintegrative disorder**

- A. Apparently normal development for at least the first two years after birth as manifested by the presence of age-appropriate verbal and nonverbal communication, social relationships, play, and adaptive behavior
- B. Clinically significant loss of previously acquired skills (before age 10 years) in at least two of the following areas:
1. expressive or receptive language
 2. social skills or adaptive behavior
 3. bowel or bladder control
 4. play
 5. motor skills
- C. Abnormalities of functioning in at least two of the following areas:
1. qualitative impairment in social interaction (e.g., impairment in nonverbal behaviors, failure to develop peer relationships, lack of social or emotional reciprocity)
 2. qualitative impairments in communication (e.g., delay or lack of spoken language, inability to initiate or sustain a conversation, stereotyped and repetitive use of language, lack of varied make-believe play)
 3. restricted, repetitive, and stereotyped patterns of behavior, interests, and activities, including motor stereotypies and mannerisms)
- D. The disturbance is not better accounted for by another specific pervasive developmental disorder or by schizophrenia.

V. **PDD NOS**

This category should be used when there is a severe and pervasive impairment in the development of reciprocal social interaction or verbal and nonverbal communication skills or when stereotyped behavior, interests, and activities are present but the criteria are not met for a specific pervasive developmental disorder, schizophrenia, schizotypal personality disorder, or avoidant personality disorder. For example, this category includes "atypical autism" – presentations that do not meet the criteria for autistic disorder because of late age at onset, atypical symptomatology, or subthreshold symptomatology, or all of these.

Appendix B

Common Questions About Autism

1. What is autism?

The Autism Society of America provides the following definition of autism:

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 coming 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 (DSM-IV-TR). The five disorders under PDD are Autistic Disorder, Asperger's Disorder, Childhood Disintegrative Disorder (CDD), Rett's Disorder, and 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 & Statistical Manual of Mental Disorders* (DSM-IV-TR).

2. Why is it sometimes difficult for someone to receive the diagnosis of autism?

Autism cannot be identified by any medical or genetic test. A diagnosis is given if an individual exhibits the behavioral characteristics of autism as defined in the *Diagnostic & Statistical Manual of Mental Disorders* (DSM-IV). These characteristics are not always clear and can sometimes appear to look like other disabilities or developmental delays. Many professionals remain unfamiliar with autism and others are hesitant to provide a diagnosis too early. The good news is that with public awareness and research on the benefits of early intervention, this is gradually changing and more children are being diagnosed at younger ages and receiving the therapeutic interventions they need.

3. What should I do if my child receives a diagnosis within the autism spectrum?

First, take it one step at a time. While autism is a lifelong disability, with early intervention your son or daughter is more likely to reach his or her potential and become a more independent adult. Continue to have high expectations for your child, but be prepared to modify those expectations based on your child's abilities.

Second, educate yourself. The better understanding you have of your child and his or her disability, the easier it will be for you to arrange for necessary services for your child. Be aware that autism is a complex disability and that your child may need to access a variety of developmental, educational, behavioral and medical services. A good way to educate yourself about services is to join an autism support group and learn from other families.

Third, contact your local Infants and Toddlers Program or Child Find Office; they can be found in every county and in Baltimore City. They will assist you in arranging for a comprehensive evaluation to determine the needs of your child.

Finally, you will quickly discover that many people are available to assist you. These individuals are referred to as a “team” because they come from different professional backgrounds to form a multidisciplinary team. With you, this team will map out expectations and goals for your child. As a parent, you are a key member of the team who will be a consistent influence throughout the lifespan of your child. It is important that you ask questions of, solicit advice from, provide information to, and have meaningful participation in team meetings.

4. How will I know what services my child with autism needs?

The services for your child are determined by the team, of which you are a member, and are based on your child’s individual needs. There is a wide array of characteristics of autism ranging from mild to severe. The team’s goal is to first identify the strengths and needs of your child, to develop goals, and then determine services that will help your child reach those goals.

5. What types of services are out there?

Here is where your knowledge becomes very important. As more children have been diagnosed with autism, there has been an upsurge in different types of interventions. Some of these interventions (or services) have successful and proven track records. Others have very little proof of success, but are touted as “cures.” It is important that you become educated about how to determine what interventions are effective.

6. When should interventions start?

As soon as autism is suspected, interventions should be planned and implemented. While experts may have different approaches to treating autism, all agree that appropriate early intervention will have the greatest influence on a child’s rate and degree of progress.

7. Do some interventions work better than others?

No one type of intervention works for every child with autism, however there are “best practices” that professionals agree should be part of every child’s early intervention programming. They include family involvement, a multidisciplinary team, a functional approach to challenging behaviors, and appropriate amounts of direct intervention. Your child’s intervention program should emphasize skill development in basic areas (ie. communication, social interactions, imitation), establish predictable routines, and take place in natural or least restrictive environments to assist with generalization and provide opportunities for interaction with typical peers. Finally, the team should select instructional strategies, techniques, and methodologies based on the developmental level of your child, your child’s learning style, and the skill or task to be taught.

8. Are there other services to help my family?

You may need respite care (to give you an occasional break from caregiving), behavioral support services, or other family support services. Ask your team or parent support group about what resources might be available to you.

Appendix C
Assessment Tools

This list does not include all materials that may be selected as the most appropriate instruments for any child. Appearance on this list does not in any way imply endorsement by the Maryland State Department of Education. Each evaluator is responsible for ensuring that the instruments he/she uses are valid, reliable, and used in the ways intended by the authors, with the populations represented by the norming sample for the instruments. Each assessment tool is identified on the first line, and the publisher is provided on the second line.

Assessment Instruments Specific To Autism

Assessment of Basic Language and Learning Skills (The ABLLS): An Assessment, Curriculum Guide, and Skills Tracking System for Children with Autism or Other Developmental Disabilities
James W. Partington, Ph.D. and Mark L. Sundberg, Ph.D.,
Behavior Analysts, Inc., 1941 Oak Park Blvd., Suite 30, Pleasant Hill, CA 94523

Autism Diagnostic Interview-Revised (ADI-R)
Catherine Lord, Department of Psychiatry, University of Chicago, 5841 S. Maryland Avenue,
MC 3077, Chicago, IL 60637

Autism Diagnostic Observation Schedule
Western Psychological Services, 12031 Wilshire Blvd., Los Angeles, CA 90025-1251

Autism Screening Instrument of Educational Planning Second Edition (ASIEP-2)
Pro Ed, 8700 Shoal Creek Blvd. Austin, TX 78757

Checklist for Autism in Toddlers (CHAT)
Baron-Cohen et al., *The British Journal of Psychiatry* (1996) pp. 158-163

Childhood Autism Rating Scale (CARS)
Western Psychological Services, 12031 Wilshire Blvd., Los Angeles, CA 90025-1251

Diagnostic Check List for Behavior-Disturbed Children (Form E-2)
Autism Research Institute, 4182 Adams Ave., San Diego, CA 92116

Gilliam Autism Rating Scale (GARS)
Pro Ed, 8700 Shoal Creek Blvd. Austin, TX 78757

Psychoeducational Profile Revised (PEP-R)
Pro Ed, 8700 Shoal Creek Blvd. Austin, TX 78757

Measures of Development and Adaptive Behavior

Battelle Developmental Inventory (BDI)
The Riverside Publishing Co., 425 Spring Lake Dr. Itasca, IL 60143-2079

Behavior Assessment System for Children (BASC)
American Guidance Services, Publisher's Building, Circle Pines, MN 55014

Brigance Inventory of Early Development

Curriculum Associates, 5 Esquire Rd., Billenica, MA 01862

Developmental Profile II

Western Psychological Services, 12031 Wilshire Blvd., Los Angeles, CA 90025-1251

Early Learning Accomplishments Profile (ELAP)

Kaplan School Supply, 888 Seventh Ave., New York, NY 10106

Scales of Independent Behavior – Revised (SIB-R)

The Riverside Publishing Co., 425 Spring Lake Dr., Itasca, IL 60143-2079

Southern California Ordinal Scales of Development (SCOSD)

Western Psychological Services, 12031 Wilshire Blvd., Los Angeles, CA 90025-1251

Vineland Adaptive Behavior Scales (VABS)

American Guidance Services, Inc. Publisher's Building, Circle Pines, MN 55014

Communication Instruments

Assessing Semantic Skills Through Everyday Themes (ASSET)

LinguiSystems, 3100 4th Ave., East Moline, IL 61244

Clinical Evaluation of Language Fundamentals – Preschool (CELF-P)

The Psychological Corporation, 555 Academic Court, San Antonio, TX 78204-2498

Expressive One-Word Picture Vocabulary Test – Revised (EOWPVT-R)

Academic Therapy, 20 Commercial Blvd., Novato, CA 94949

Functional Communications Profile

LinguiSystems, 3100 4th Ave., East Moline, IL 61244

The National Test for Receptive/Expressive Language

Don Johnston Inc., 100 N. Rand Rd. Bldg. 115, PO Box 639, Wauconda, IL 60084

Peabody Picture Vocabulary Test – Revised (PPVT-R)

American Guidance Services Inc., Publisher's Building, Circle Pines, MN 55014

Preschool Language Scales – 3 (PLS-3)

The Psychological Corporation, 555 Academic Court, San Antonio, TX 78204-2498

Receptive One-Word Picture Vocabulary Test – Revised (ROWPVT-R)

Academic Therapy, 20 Commercial Blvd., Novato, CA 94949

Reynell Developmental Language Scales

Western Psychological Services, 12031 Wilshire Blvd., Los Angeles, CA 90025-1251

Rossetti Infant-Toddler Language Scale
LinguiSystems, 3100 4th Ave., East Moline, IL 61244

Measures of Intellectual Cognitive Skills

Bayley's Scales of Infant Development II (BSID-II)
The Psychological Corporation, 555 Academic Court, San Antonio, TX 78204-2498

Columbia Mental Maturity Scale (CMMS) Nonverbal
The Psychological Corporation, 555 Academic Court, San Antonio, TX 78204-2498

Differential Ability Scales (DAS)
The Psychological Corporation, 555 Academic Court, San Antonio, TX 78204-2498

Leiter International Performance Scale – 2 (LIPS) Nonverbal
Stoelting Company 1350 South Kostner Ave., Chicago, IL 60623

Merrill-Palmer Scale of Mental Tests (MPSMT) Nonverbal
Stoelting Company 1350 South Kostner Ave., Chicago, IL 60623

Stanford-Binet Intelligence Scale 4th Edition (SBFE)
The Riverside Publishing Co., 425 Spring Lake Dr. Itasca, IL 60143-2079

Test of Nonverbal Intelligence – 2 (TONI-2) Nonverbal
Pro Ed, 8700 Shoal Creed Blvd., Austin, TX 78757

Wechsler Preschool and Primary Scale of Intelligence- Revised (WPPSI-R)
The Psychological Corporation, 555 Academic Court, San Antonio, TX 78204-2498

Academic Instruments

Bracken Basic Concept Scale (BBCS)
The Psychological Corporation, 555 Academic Court, San Antonio, TX 78204-2498

Brigance Inventory of Basic Skills
Curriculum Associates, 5 Esquire Rd., Billerica, MA 01862

Kaufman Survey of Early Academic and Language Skills (KSEALS)
American Guidance Services Inc., Publisher's Building, Circle Pines, MN 55014

Appendix D
Local Infants and Toddlers Offices

Allegheny County Infants & Toddlers Program

Allegheny County Public Schools
Beall Elementary School
College Avenue
Frostburg, MD 21532
301-689-0466 (fax) 301-689-3834

Anne Arundel County Infants & Toddlers Program

Anne Arundel County Public Schools
Woodside Elementary School
160 Funke Road
Glen Burnie, MD 21061
410-222-6911 (fax) 410-222-6916

Baltimore City Infants & Toddlers Program

Baltimore City Health Department
10 W. Eager Street, 2nd floor
Baltimore, MD 21201
410-396-1666 (fax) 410-547-8292

Baltimore County Infants & Toddlers Program

Office of Special Education
6901 North Charles Street, ESS Building
Baltimore, MD 21204
410-887-2169 (fax) 410-583-8736

Calvert County Infants & Toddlers Program

Calvert County Health Department
975 Solomons Island Road, North
Prince Frederick, MD 20678
410-535-5400 ext 388 (fax) 410-535-5285

Caroline County Infants & Toddlers Program

Caroline County Health Department
403 S. Seventh Street
Denton, MD 21629
410-479-4419 (fax) 410-479-4871

Carroll County Infants & Toddlers Program

Carroll County Health Department
Carroll Springs Elementary School
495 South Center Street
Westminster, MD 21157-5635
410-876-4437 x 221 (fax) 410-751-3928

Cecil County Infants & Toddlers Program

Cecil County Public Schools
201 Booth Street
Elkton, MD 21921
410-996-5444 (fax) 410-996-5454

Charles County Infants & Toddlers Program

Charles County Health Department
P.O. Box 1040,
4545 Crain Highway
White Plains, MD 20695
301-609-6808 (fax) 301-934-4632

Dorchester County Infants & Toddlers Program

Dorchester County Public Schools
P.O. Box 619
700 Glasgow Street
Cambridge, MD 21613
410-221-0837 (fax) 410-221-5207

Frederick County Infants & Toddlers Program

Frederick County Developmental Center
350 Montevue Lane
Frederick, MD 21702
301-694-1612 (fax) 301-631-3280

Garrett County Infants & Toddlers Program

Garret County Office of Childhood and Youth
12423 Garrett Highway
Oakland, MD 21550-0059
301-334-1189 (fax) 301-334-1893

Harford County Infants & Toddlers Program

Harford County Health Department
John Archer School
100 Thomas Run Road
Bel Air, MD 21015
410-638-3823 (fax) 410-638-3825

Howard County Infants & Toddlers Program

Howard County Public Schools
Faulkner Ridge Center
10598 Marble Faun Court
Columbia, MD 21044
410-313-7017 (fax) 410-313-7103

Kent County Infants & Toddlers Program

Kent County Board of Education
215 Washington Avenue
Chestertown, MD 21620
410-778-7038 (fax) 410-778-6193

Montgomery County Infants & Toddlers Program

Montgomery County Health & Human Services
401 Fleet Street, LL3C
Rockville, MD 20850
240-777-3997 (fax) 240-777-4447

Prince George's County Infants & Toddlers Program

Prince George's County Dept. of Family Support Services
5021 Rhode Island Road, Suite 102
Hyattsville, MD 20781
301-985-3811 (fax) 301-985-3801

Queen Anne's County Infants & Toddlers Program

Queen Anne's County Public Schools
202 Chesterfield Avenue
Centreville, MD 21617
410-758-2403 ext.180 (fax) 410-758-8206

Somerset County Infants & Toddlers Program

Somerset County Public Schools
30411 Mt. Vernon Road
Princess Anne, MD 21853
410-651-1485 (fax) 410-968-1178

St. Mary's County Infants & Toddlers Program

Saint Mary's County Health Department
P.O. Box 316
Peabody Street
Leonardtown, MD 20650-0316
301-475-4393 (fax) 301-475-4350

Talbot County Infants & Toddlers Program

Talbot County Public Schools
P.O. Box 1029
Washington Street
Easton, MD 21601
410-820-0319 (fax) 410-820-4260

Washington County Infants & Toddlers Program

Washington County Public Schools
1350 Marshall Street
Hagerstown, MD 21740
301-766-8217 (fax) 301-791-6716

Wicomico County Infants & Toddlers Program

Wicomico County Health Department
108 East Main Street
Salisbury, MD 21801
410-543-6920 (fax) 410-219-2822

Worcester County Infants & Toddlers Program

Worcester County Public Schools
6270 Worcester Highway
Newark, MD 21841
410-632-2582 X233 (fax) 410-632-0364

Appendix E

Instructional Methods and Strategies

There are numerous instructional approaches, treatment protocols, and specialized programs which have been proven through research, review of outcome data, and observation to be effective with children with autism. Team members including parents select intervention strategies, techniques, and methodology based on the:

- Developmental level of the child
- Child's learning style, strengths, and needs
- Skill or task to be learned.

The following strategies and intervention approaches may be considered when developing personalized programs for young children with autism:

- Incidental Teaching
- Normalization and Developmentally Appropriate Practice
- Naturalistic Teaching Strategies
- Developmental, Individual Differences, Relationship-Based Approach (DIR)
- Family-Guided Routines-Based Intervention
- Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH) Strategies
- Applied Behavior Analysis and Discrete Trial Training
- Positive Behavioral Supports
- Assistive Technology
- Sensory Intervention Plans
- Verbal Behavior
- Other Approaches.

It should be noted that different approaches or models use some of the same strategies and are based on similar principles; for example, *Behavioral Principles in Naturally Occurring Activities* includes elements of *Applied Behavioral Analysis*, *Developmentally Appropriate Practices*, *Naturalistic Teaching Strategies*, and *Family-Guided Routines-Based Intervention*. The approaches may be contrasted on a number of variables which Cole and others have used in comparing direct instruction and mediated learning:

- Teacher versus child initiation of interaction
- Use of secondary reinforcement versus naturally occurring consequences
- Use of elicited responding versus modeling
- Use of predetermined stimulus material versus naturally occurring environmental stimuli
- Predetermined sequence of instruction versus variable sequence of instruction
- Goal selection based on didactic principles versus goal selection based on the sequence of normal development.

INCIDENTAL TEACHING

Dr. Gail McGee, director of Emory University's Walden Program for children with autism, describes incidental teaching as "a systematic protocol of instruction that is provided in the context of natural environments" (McGee, 1999). Incidental teaching evolved from the field of Applied Behavior Analysis (ABA), which has developed a form of language instruction that works well for many children with autism. Incidental teaching has the same principles of learning as found in discrete trial training, following the same technical conditions:

- The intervention is composed of operant conditioning techniques;
- The intervention goals are socially significant; and
- The intervention results are analyzed objectively by assessing each child's progress before, during, and after the intervention.

The Walden Program, which was developed using incidental teaching includes a strong family training component, as well as planned environmental arrangement to illicit communication.

- A natural environment is arranged to attract children to desired materials and activities
- The child "initiates" the teaching process by indicating an interest in an item or topic
- The teacher uses the child's initiation as an opportunity to prompt an elaboration
- The child's correct response to the teacher's prompt results in a confirming response, then contingent access to the item/topic of interest.

NORMALIZATION AND DEVELOPMENTALLY APPROPRIATE PRACTICE

Normalization and Developmentally Appropriate Practice involves the use of instructional strategies which approximate those used with same-age typical peers. These strategies reflect developmentally appropriate practices by providing opportunities for children to choose from a variety of activities and materials, facilitating children's engagement, and extending children's learning by asking questions or making suggestions. Structuring and arranging the physical, social, and temporal dimensions of the classroom environment are also used.

Developmentally appropriate practice is:

- A philosophy for teaching young children
- A set of principles, not a methodology
- An approach that takes into account those aspects of teaching and learning that change with the age and experience of the learner.

The dimensions of developmentally appropriate practice include:

- Age appropriateness (reflects what we know about how children develop and learn)
- Individual appropriateness (takes into account each child's own development, interests, learning styles, and cultural background)
- Emphasis on child-initiated activities in the context of relevant experiences
- Active engagement and participation
- Emphasis on social interactions

- Teacher’s responsiveness to children’s behavior.

DEVELOPMENTAL, INDIVIDUAL DIFFERENCES, RELATIONSHIP-BASED APPROACH (DIR)

The Developmental, Individual Differences, Relationship-based Approach (DIR) is a comprehensive, interdisciplinary approach developed by Drs. Stanley Greenspan and Serena Wieder. The relationship-based approach focuses on using an intensive integrated intervention which is individualized to match the child’s level in the social-interaction development hierarchy. Relationship-based developmental experiences build skills in the core processes of relating, attending, communicating, and thinking. Difficulties in relating and communicating are believed to be secondary to sensory and motor processing deficits. The ultimate goal of the intervention is to help the child develop appropriate affect and form a sense of self as an intentional and interactive individual. Parents and primary caregivers are taught specific strategies which are utilized during eight to ten sessions (20-30 minutes each) per day of “floortime” play with the child.

“Floortime” is a series of reciprocal child-directed interactions resulting in “communication circles.” The goal of “floortime” is to sustain interactions between the child and the adult by gradually increasing the circles of communication. These interactions become the basis for further play development.

During “floortime,” the adult joins in the child’s play to increase opportunities for pleasurable interaction and engagement. The child’s actions are considered intentional and purposeful. The adult follows the child’s lead to validate the child’s sense of self. Preferred objects and activities are used to motivate the child and facilitate persistence and patience. Higher level skills and concepts are taught through interactive play. “Floortime” also provides for peer experiences with typically-developing age-mates.

FAMILY-GUIDED ROUTINES-BASED INTERVENTION

Family-guided routines based intervention is a systematic approach to embed intervention consistently by all family members and service providers throughout the day rather than in individual, isolated therapy sessions. Routines are functional events of daily living that offer opportunities to teach and practice meaningful skills in settings and situations as they are needed. By definition, they occur on a regular basis and are repeated frequently, offering multiple opportunities for teaching and learning. Family-guided routines are those functional and predictable activities that match the interests and individual schedules of the child and family. The family guides the selection of appropriate targets and contexts for intervention. Routines which are selected for intervention are predictable and positive for both the child and care provider to enhance the ease of use and the potential for positive outcomes.

The following basic steps help to ensure that service providers are working collaboratively with the family to support learning and development.

1. Identify the general schedule of the child’s and family’s day including typical routines. Identify the family’s priorities and concerns relating to the child’s skills and daily routines. Identify outcomes.
2. Select preferred daily routines. Consider the child’s strengths and needs as well as the family’s strengths and needs.
3. Select intervention techniques to meet the outcomes. Build intervention techniques and activities upon natural strategies used by care providers.

4. Discuss plans with service providers and implement strategies across environments and activities.
5. Teach new strategies and model when appropriate.
6. Monitor progress, revise and adjust strategies, and gather feedback.

A schedule matrix which identifies the routines selected for embedding intervention, the outcomes to be targeted, and the strategies to use to support the child's learning when the opportunity occurs is developed with the family and the service providers.

TREATMENT AND EDUCATION OF AUTISTIC AND RELATED COMMUNICATION HANDICAPPED CHILDREN (TEACCH) STRATEGIES

The TEACCH program, developed at the University of North Carolina at Chapel Hill, provides community-based services to children with autism and related disorders from preschool age through adulthood. The school program offers individualized instruction emphasizing skills appropriate for the child's age and developmental level in a highly structured learning environment. General domains for skill development are communication, socialization, practical skills, and a fostering of independence and preparation for adult living. Children of preschool-age enrolled in traditional TEACCH models may attend half-day or full-day programs. Typical classrooms for preschoolers have six students with autism, one teacher, and one assistant teacher. Additional related services such as speech-language therapy may be provided at school.

The key elements of structured teaching include:

Highly Structured Learning Environments

The learning environment is clearly defined with concrete physical boundaries. Separate areas are designed for specific activities including independent work stations, play areas, and group work areas. Work areas are free of distractions. Visual organization, visual clarity, and visual instruction are stressed throughout the environment and routine.

Daily Individual Schedules

A personal schedule is designed for each student. The daily routine is displayed visually through picture symbols, photographs, line drawings, and written words in a top to bottom or left to right progression. The student is taught to manipulate the schedule independently. Activities within the schedule may be color-coded (independent work - yellow; circle time - red, etc.)

Individual Work Systems

Work tasks for specific skills are physically displayed in baskets with the "work" to be completed placed to the student's left. The student completes tasks independently and places the materials in a basket to his right. The exact task and amount of work are clearly defined. Initial tasks are taught utilizing chaining* and shaping+ techniques until independence is achieved. Upon completing work, the student refers to his individual schedule to transition to the next activity. Work tasks are changed frequently as the student progresses. Examples of work tasks

* Chaining means breaking a complex task into components then teaching one component to mastery prior to teaching the remaining components in a sequential manner.

+ Shaping means teaching a new behavior by reinforcing approximations of the desired response.

for younger children include: matching, sorting and sequencing activities, assembly activities, and functional academics (pre-math and pre-reading).

Curriculum

The curriculum is developmentally sequenced and functionally based. Key areas include functional communication, vocational and independence training, community-based instruction, and leisure and social training.

Family Involvement

Training of family members to carry over activities in the home is strongly encouraged. The home environment may be modified to provide visual structure. Families may request packets of activities which are completed at home. These packets contain instructions, material lists, and feedback forms. Communication between home and school is frequent through direct contact or communication notebooks.

APPLIED BEHAVIOR ANALYSIS & DISCRETE TRIAL TRAINING

Applied behavior analysis (ABA)* comprises interventions obtained from the principles of behavior analysis designed to analyze and change behavior in a precisely measurable and accountable manner. It employs strategies based on scientific principles of behavior that are designed to build socially useful repertoires and reduce problematic ones. The defining assumption of ABA is that behavior is learned and controlled by contingencies within the environment.

The ABA model has been used very effectively to change behavior in many diverse areas. The model has been especially effective in developing, implementing, and evaluating instructional programs for children and youth with autism. The literature shows that, for this group of students, instruction can be presented in a variety of ways (incidental teaching, discrete trial, natural language paradigm, etc.) and still be considered a behavior analysis approach. Many behavior analysts, however, advocate that instruction for individuals with autism should be presented in a “discrete trial” format. A discrete trial consists of four parts:

- An instruction stated as concisely as possible, for example, “Come here,” versus “I want you to come here, please.” The request may be presented with a prompt (assistance) that is reduced systematically as the child responds more independently.
- A response from the child that may take several forms including successful completion (a correct response), partial success, noncompliance, or unresponsiveness. The latter two would be considered incorrect responses.
- A consequence provided by the practitioner (classroom teaching staff, parent, therapist) that corresponds to the child’s response. Correct responses enable the child to access some highly preferred item as a reinforcer, for example, verbal praise, toy play, tickling, edibles, sensory stimulation, etc. Incorrect responses are followed by feedback indication the child’s response was inaccurate. Such feedback may include

* Applied Behavior Analysis is sometimes used interchangeably with “Lovaas Therapy.” The groundbreaking work of Dr. O. Ivar Lovaas, one of the earliest pioneers in the behavioral treatment of young children with autism, is one example of the use of Applied Behavior Analysis.

- saying “No,” and removing materials and attention for one to two seconds before repeating the instruction.
- An inter-trial interval. This refers to the teacher pausing briefly after providing a consequence and before starting the next trial. An inter-trial interval helps to ensure that each trial is discrete from the next trial.

Teaching staff using this model may provide instruction initially when seated at a table with the child directly across from them. This may occur to help establish student responsiveness to the teacher. However, discrete trial instruction can be provided in any situation in and out of the classroom setting.

Specific Strategies include:

- Targeted skills are broken down into small attainable tasks.
- Targeted skills are based upon the child’s individual needs (teaching sessions may cover a wide range of developmentally appropriate behaviors including imitation, receptive/expressive discriminations, communication, peer interaction and play, as well a challenging behaviors such as tantrums and noncompliance).
- Skills are developed in a hierarchical manner.
- Highly preferred materials are identified systematically and are available as reinforcers throughout the day.
- Skills are encouraged by reinforcing desired behaviors systematically, and ignoring, redirecting, or discouraging challenging behaviors.
- Complex skills are taught through the use of chaining.
- Mastery of a skill is based on a numerical criterion, for example, a percentage.
- Progress is closely monitored by continuously collecting and analyzing child performance data.
- Changes in instruction occur as a function of child performance data.
- Newly mastered skills are reviewed to ensure retention.
- Newly mastered skills are adapted to ensure the generalization of skills across persons, materials, and locations.
- Skills are practiced in progressively less structured settings and more natural situations to ensure generalization across increasingly variable situations; for example, children may answer questions in a group setting while taking turns with peers.

POSITIVE BEHAVIORAL SUPPORTS

Positive behavioral supports are used within a program to promote behavioral change. They are built on the following assumptions about behavior and the effectiveness of interventions:

- Challenging behaviors serve a function for the child.
- Challenging behaviors are context related.
- Effective interventions are based on a thorough understanding of the problem behavior.
- Behavior support plans should be guided by a strong value base.

Positive behavior supports are driven by a thorough understanding of the problem behavior and its function. Interventions are related to specific hypotheses that address the function of the behavior. Reduction of problem behaviors is a result of teaching alternative skills and modifying the child’s environment. Positive behavioral supports include multiple interventions to increase

the plan's effectiveness. These may include teaching alternative skills, modifying antecedent and setting events, implementing consequence strategies, and designing crisis management procedures. The positive behavioral supports approach holds a broadened view of intervention success by evaluating whether improvements in the use of alternative behaviors have been maintained across time and generalized across settings, whether improvements have occurred in the child's quality of life, and whether the intervention has positively impacted on the child's health and well-being. Positive behavioral supports are process-oriented, requiring ongoing team problem solving for understanding the nature of the problem and for designing effective behavioral support plans.

This approach uses multiple intervention strategies to build long lasting behavioral change. It blends effective practices in both instruction and behavior management to produce meaningful results. A collaborative team approach is helpful in identifying antecedent strategies such as instructional modifications, schedule changes, or environmental changes; alternative skills training; consequence strategies; and long-term prevention strategies. A problem-solving process which includes the following elements is used in developing a personalized plan for an individual child:

- Identify the behavior.
- Assess the behavior.
- Develop hypothesis statements.
- Select intervention strategies and modifications.
- Write a plan.
- Implement the personalized plan.
- Document progress.
- Evaluate the effectiveness of the plan.
- Modify or terminate the plan.

The written plan includes:

- Background information
- Description of the problem and statement of current performance
- Goal statements for performance
- Hypotheses statements for the function of the behavior
- Intervention strategies related to the function of the behavior
- Specific evaluation procedures
- Supports needed for implementors.

ASSISTIVE TECHNOLOGY

Assistive technology is 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. Examples of assistive technology often used with young children include:

- Adapted toys and switches
- Home modifications
- Low tech and high tech voice output communication devices
- Mobility aids such as wheelchairs or scooter boards
- Environmental controls

- Feeding aids, tub seats, etc.
- Computer adaptations.

The use of assistive technology is a strategy or modification which should be included in a child's Individualized Family Service Plan (IFSP) or Individualized Education Plan (IEP) if required to achieve specified outcomes or goals.

The most widely used assistive technology applications for young children with autism include those which address communication skills and concept development through the use of the computer.

Low Tech Augmentative Communication Aids

Strategies and devices which supplement speech skills are typically termed "augmentative communication" approaches. Materials which do not have electronic components are often referred to as "low tech" augmentative communication aids and include picture symbol communication boards and books. For preliterate children, words and concepts are represented by photographs or picture symbols which accompany the printed words. Messages are communicated by pointing to the corresponding picture symbols or by handing the picture symbol to a communication partner.

Picture Exchange Communication System (PECS)

The Picture Exchange Communication System (PECS) is a structured training program which teaches children to communicate by selecting picture symbols or words from a display and handing them to a communication partner. PECS is widely used with children with autism due to the frequent difficulties which many children encounter with developing purposeful pointing skills.

High Tech Voice Output Communication Aids

Augmentative communication devices which have electronic components are often referred to as "high tech." These devices permit an adult to program corresponding spoken messages for the picture symbols selected for a child. The child is able to communicate the messages by selecting a picture symbol. The spoken message often provides a model for the child and cues the child to say the word or phrase. Use of a voice output communication device also permits the child to communicate more effectively in group situations than use of low tech communication aids.

Computer Adaptations

The computer is an excellent learning tool and alternative to handwritten communication for young children with autism. As a learning tool, the computer provides consistent feedback and opportunities for repeated practice of skills. Many young children are engaged by the graphics presented by the software and attend to the computer for extended periods of time. Adaptations to the input method make it possible to provide computer-assisted instruction for very young children and children who are unable to effectively use the standard keyboard or mouse. Expanded keyboards, such as Intellikeys, provide the ability to enlarge the key size and customize letter or picture overlays which correspond to the software programs. Touch windows provide alternatives to the mouse for young children who are able to point to items displayed on the monitor to make selections. Specialized software programs which provide speech feedback are frequently used with young children as they develop early literacy skills.

SENSORY INTERVENTION PLANS

Sensory processing refers to the ability of the central nervous system to take in and respond to environmental input from all of the senses, including vision, hearing, touch, responses to movement and pressure on the body, taste, and smell. Self-regulation refers to the ability to maintain a calm, alert, and attentive state which promotes involvement in learning experiences and interaction with others. Many people with autism are believed to demonstrate atypical reactions to sensory input. The self-stimulatory or perseverative behaviors exhibited by persons with autism are possibly attempts to seek out calming and organizing sensory input or to avoid disorganizing input from the environment. Examples of difficulty with sensory processing and self-regulation may include:

- Excessive jumping, running, or spinning which indicates a need for vestibular (movement of the head through space) and proprioceptive (movement and position of the body) input
- Biting, sucking, and chewing excessively which indicates a need for proprioceptive input through the mouth
- Excessive touching or avoidance of touching which indicates atypical reactions from the tactile (touch) system
- Agitated behavior or under-responsive behavior in loud, crowded, or visually stimulating situations which indicates over-reactivity to noise, touch, or visual input.

Difficulties with sensory processing and self-regulation can be addressed through careful assessment of the individual student's needs. A sensory intervention plan is developed based on the specific sensory needs of the child. The learning environment is modified to reduce sensory defensiveness and enhance self-regulation. Specific activities are planned throughout the student's day to promote better attention and engagement in learning. If the team identifies self-regulation related to sensory processing difficulties as a need related to the child's education, the Individualized Education Program (IEP) lists the use of a sensory intervention plan as a modification or strategy.

VERBAL BEHAVIOR

Verbal Behavior, sometimes referred to as Verbal Behavior Analysis or VBA, uses the principles of applied behavioral analysis and is similar in method to discrete trial training. This approach is based on B. F. Skinner's analysis of verbal behavior and uses errorless teaching, specific quick-transfer (prompting and fading) procedures, and the use of both discrete trial training in the natural environment and during intensive teaching sessions. Children with no spoken language are often taught the use of sign language as a communication "bridge."

OTHER TREATMENT PROTOCOLS AND SPECIALIZED PROGRAMS

What follows is an overview of other treatment options available to individuals with autism. This is not an exhaustive list, and it is intended to provide a general overview of available options as opposed to specific treatment recommendations. Some of the therapies and treatments listed in this next section are not viewed as credible approaches by some medical and professional associations.

Auditory Integration Training

The technique of auditory integration training may help some individuals who are oversensitive (hypersensitive) to sounds. The individual listens to a variety of sound frequencies, coordinated to his or her level of impairment. Auditory training is performed by an audiologist trained in this method.

Diet/Vitamins

Some individuals with autism exhibit low tolerance for and/or allergies to a variety of substances, such as yeast and gluten. Although no rigorous scientific studies support the idea that dietary modifications reduce or eliminate symptoms of autism, some professionals and parents have reported positive changes in behavior following the modifications. Vitamin supplements have been reported by some parents to affect particular behaviors, such as increasing attention spans.

Facilitated Communication

Facilitated communication is a technique by which a trained professional, the "facilitator," supports the hand, arm or shoulder of the individual who has communication impairments. This method helps the individual to point to or press the keys of a communication device to spell out words.

Medications

There is no single medication to treat autism, but a wide variety of them have been prescribed to alleviate symptoms such as aggression, seizures, inattention, hyperactivity, anxiety or obsessive/compulsive behaviors. For information on the use of medications, parents should consult a physician who has experience in treating the symptoms of autism.

Music Therapy

When used in a structured setting, music can be incorporated into the teaching of cognitive, motor and daily living skills. Effective for some individuals with autism, music therapy may be provided in a private setting or included in a child's early intervention or school program.

Vision

Some individuals with autism experience vision difficulties, such as poor eye contact, difficulty with visual attending, visual fixation and hyper- or hypo- sensitivity to light and/or color. Developmental or behavioral optometrists may be able to treat them. They believe that some of the unusual behaviors associated with autism may be related to visual-perceptual problems. Treatments include specialized colored or prism lenses and vision exercises.

Other Treatments

The treatments mentioned above are not a comprehensive list of all options available to individuals with autism. There are a variety of others, including therapy using animals, treatments to reduce yeast in the body and cranial-sacral therapy. Families and professionals are advised to research and evaluate all treatments carefully.

Appendix F

Child Care Resources

Parents of children with autism and other disabilities report difficulty in locating and maintaining child and after-school care for their children. Families seeking child care should be referred to:

The Special Needs Enhanced Counseling Service

LOCATE: Child Care

Maryland Committee for Children (MCC)

410-625-1113 (Baltimore Metro Area)

1-800-999-0120 (Outside the Baltimore Area)

410-485-1042 (TDD)

The Maryland Committee for Children (MCC) developed the LOCATE: Child Care Special Needs Enhanced Counseling Service through a grant from the Maryland State Department of Education. Any parent in Maryland who has a child or children with disabilities, ages birth through 21 years of age, may access The Special Needs Enhanced Counseling Service. This service offers specialized one on one assistance and support to parents in need of child care.

When a parent contacts LOCATE for child care information, the LOCATE counselor will:

- Discuss the parent's child care preferences such as type of care, location, cost and other pertinent variables;
- Discuss the child's disability and any services or accommodations needed;
- Explain the Americans with Disabilities Act as it applies to child care;
- Explain the type of child care available;
- Call providers or programs to identify child care vacancies for the family and to explain the child's special need to the provider;
- Provide current information on early childhood education, what to look for in quality child care and best child care practices;
- Link the caller to other resources such as the state subsidy program, Purchase of Care, the Earned Income Tax Credit, and other programs and,
- Offer referrals to community resources such as respite, mental health facilities, financial assistance, job development programs, parent support groups, and transportation.

Project ACT (All Children Together)

Abilities Network, Inc.

410-828-7700 (Baltimore)

1-800-492-2523 (Outside the Baltimore Area)

Fax: 410-828-7708

Project ACT works with childcare providers and early childhood professionals to educate them in the skills essential to caring for children with diverse needs in inclusive community settings.

Project ACT services may include:

- On-site observation and consultation
- Informal assessment and referral to appropriate resources
- Individual, on-site support short term and long term) in the childcare setting
- Access to individualized adaptive materials
- Liaison services between the childcare provider, families, and school systems
- Training individualized to a specific child offered on-site to providers

Appendix G
Family Support Services through the
Developmental Disabilities Administration

Families of children with autism and other developmental disabilities should also be referred to the Developmental Disabilities Administration (DDA) or a local service provider regarding Family Support Services. Family Support Services (FSS) are an array of services and assistance, based on each family's unique needs, that are provided to families with children who have developmental disabilities. Family support services might include:

- Information and referral
- Assistance in identifying needs
- Advocacy to obtain needed services or benefits
- Assistance locating and acquiring services like:
 - ✓ Respite and child care
 - ✓ Adaptive equipment and assistive technology
 - ✓ Educational aids and toys
 - ✓ Accessibility modifications to the family's home or car
 - ✓ Support groups
 - ✓ Parent education
 - ✓ Special diets, clothing, and personal care items
 - ✓ Home health care and other in-home assistance
 - ✓ Social and recreational activities
 - ✓ Transportation to medical and other important appointments
 - ✓ Medical and dental expenses not covered by insurance
 - ✓ Other services and supports unique to each family's needs

Families in Maryland who have a child under age 22 with a developmental disability who is living at home are eligible for DDA Family Support Services. Developmental disabilities include, but are not limited to mental retardation, cerebral palsy, epilepsy, autism, and brain injury. A child must meet the DDA's definition of developmental disability; most children with autism fit this definition. Parents should know that family support services are not an entitlement, which means they may not be available to all eligible families because of limited funding. Family support Services are provided by local agencies with funding from the DDA. To apply for services, contact a local FSS provider directly. A list of FSS providers is available on the DDA website at <http://www.ddamaryland.org> or by calling a DDA Regional Office.

Central Maryland Region

Baltimore City and Anne Arundel, Baltimore, Harford, and Howard Counties: 410-902-4500

Southern Maryland Region

Charles, Calvert, Montgomery, Prince George's, and St. Mary's Counties: 301-362-5100

Eastern Shore Region

Caroline, Cecil, Dorchester, Kent, Queen Anne's, Somerset, Talbot, Wicomico, and Worcester Counties: 410-334-6920

Western Maryland Region

Allegany, Carroll, Frederick, Garrett, and Washington Counties: 301-7914670

Appendix H

Glossary of Terms

ABA – The abbreviation for Applied Behavior Analysis. *See Applied Behavior Analysis.*

ADA – The abbreviation for Americans with Disabilities Act. *See Americans with Disabilities Act.*

Adaptive Behavior – The ability to adjust to new situations and to apply familiar or new skills to those situations. For example, a two-year-old is displaying his ability to adapt when he says, “Mine!” to the child who is attempting to take his toy. A five-year-old shows adaptive behavior when he is able to use the same table manners he uses at home at a friend’s house.

Advocate – An individual who represents or speaks out on behalf of another person’s interests (as in a parent on behalf of his or her child).

Age-appropriate intervention – Materials and activities designed to teach the child with special needs are appropriate for the child’s typically developing same-age peers. For instance, a toy designed for use with typically developing one-year-old children should not be used with a child who is eight years old, but who has the developmental abilities of a one-year-old.

Americans with Disabilities Act (ADA) – Federal civil rights law protecting individuals with disabilities. Enacted in 1990.

Annual Goal – A statement of the desired outcome of early intervention services or education for a specific child. Annual goals for early intervention are selected by the child’s parents and the child’s early intervention multidisciplinary team and are stated on the *Individualized Family Service Plan*. Annual goals for education also are developed by a team that includes the child’s parents, and are stated in the *Individual Education Plan* (IEP). Objectives may also be stated to provide developmentally appropriate activities and measurement of progress toward attainment of the goal.

Applied Behavior Analysis (ABA) – Applied Behavior Analysis (ABA) is not a particular treatment or therapy. ABA is the name of a professional field that uses principles of learning to increase performance of socially desirable behaviors. It always relies upon the collection of objective data to measure performance and the effectiveness of an intervention. ABA is used in industry, business and education as well as in the field of disabilities. The term “ABA” is sometimes used to refer to a one-on-one therapy that is named discrete trial training, however it can also be applied using an incidental teaching approach. Some educational professionals as well as parents will use the term ABA when referring to discrete trial training. *See Discrete Trial Training.*

Approach - The philosophy or paradigm that governs treatment selection and implementation.

Arc – A national organization, formerly known as the Association for Retarded Citizens, which provides advocacy services to individuals with mental retardation and their families and publishes information about mental retardation. The Arc has local and state branches throughout the United States.

ASA – The abbreviation for Autism Society of America. *See Autism Society of America.*

Asperger's Disorder – Condition found in the DSM-IV-TR manual under Pervasive Developmental Disorders. The essential features are severe and sustained impairment in social interaction and the development of restricted, repetitive patterns of behavior, interests and activities. Additional criteria are listed in the DSM-IV-TR.

Assistive Technology – Special items or equipment used to increase, maintain or improve one's functioning abilities. The term covers items such as computers, pencil holders, specialized switches and calculators.

Audiologist – A specialist who determines the presence and type of hearing impairment. An audiologist conducts hearing tests and makes recommendations for hearing aids.

Audiology – The study of hearing and hearing disorders.

Audiometric Testing – Tests to measure the ability to hear sounds of varying frequency (pitch) and intensity (loudness), thereby revealing any hearing impairment. Results are then recorded on an *audiogram*. Also known as audiometry.

Augmentative Communication – Any method of communicating without speech, such as by signs, gestures, picture boards, or electronic or non-electronic devices. These methods can help individuals who are unable to use speech or who need to supplement their speech to communicate effectively.

Autism – Autism is a developmental disability that typically appears during the first three years of life. The result of a neurological disorder that affects functioning of the brain, autism and its associated behaviors occur in approximately 25 of every 10,000 individuals. This means that at least one out of every 500 children born will have autism. It is important to note that some children with mental retardation, fragile X syndrome, psychiatric disorders, sensory deficits such as vision or hearing impairments, and certain rare neurological diseases have autistic-like characteristics, but do not have autism. In older literature, autism may be called infantile autism or Kanner's syndrome. *See Pervasive Developmental Disorder.*

Autism Society of America (ASA) – National nonprofit organization that promotes lifelong access and opportunities for persons within the autism spectrum. The ASA has state and local chapters throughout the United States.

Autism Spectrum Disorder – A term encompassing the condition(s) known as pervasive developmental disorder(s). *See Pervasive Developmental Disorder.*

Behavior Intervention Plan – A written document that becomes part of the IEP and which identifies problem behaviors; sets goals for decreasing unwanted behaviors and increasing desired behaviors; and outlines interventions to use when specific behaviors occur. Sometimes called a behavior management plan.

Behavioral Assessment – Gathering (through direct observation and by parent report) and analyzing information about a child's behaviors. The information may be used to help the child change unwanted behaviors. Variables that are noted include when a behavior occurs as well as its frequency and duration. *See Functional Assessment of Behavior.*

Blissymbols - A system of approximately 100 basic symbols used singly or in combination to represent virtually any message.

Central Nervous System (CNS) – The structure that consists of the brain, the spinal cord and related systems that controls all aspects of learning, thinking and movement.

CNS – *See Central Nervous System.*

Cognitive – Referring to the developmental area that involves thinking skills, including the ability to receive, process, analyze and understand information. Matching red circles and pushing the button on a mechanical toy to activate it are examples of cognitive skills.

Communication – The developmental area that involves skills which enable people to understand (receptive language) and share (expressive language) thoughts and feelings. Waving goodbye, using spontaneous single-word utterances and repeating five-word sentences are examples of communication skills.

Communication Aid – A nonverbal form of communication such as gesture, sign language, communication boards and electronic devices (for example, computers and voice synthesizers).

Communication Board/Book – A board or book with pictures or symbols that a child or adult can point to for expression of his or her needs.

Communication Disorder – Difficulty with understanding and/or expressing messages. Communication disorders include problems with articulation, voice disorders, stuttering, language disorders and some learning disabilities.

DDA – The Developmental Disabilities Administration. *See below.*

Descriptive assessment – A type of functional assessment which is based on direct observation of the behavior in the natural environment.

Developmental Delay – The term used to describe the condition of an infant or young child who is not achieving new skills in the typical time frame and/or is exhibiting behaviors that are not appropriate for his or her age. Some children who are developmentally delayed eventually have a specific diagnosis of a particular developmental disability. Other children with delays catch up with their typically developing peers.

Developmental Disability (DD) – a severe chronic disability that: is attributed to a physical or mental impairment, other than the sole diagnosis of mental illness, or to a combination of mental and physical impairments; is manifested before the individual attains the age of 22; is likely to continue indefinitely; results in the inability to live independently without external support or continuing and regular assistance; reflects the need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services that are planned and coordinated for that individual.

Developmental Disabilities Administration (DDA) – This Maryland agency funds services to people with mental retardation, autism, cerebral palsy and related disabilities. (This description is based on the State definition of developmental disability, which is used to determine who receives particular services through DDA funds.)

Developmentally appropriate intervention –Teaching of skills acquisition is targeted at the child’s current developmental level, looking at the child’s current abilities across developmental domains (communication, social, cognitive, adaptive behavior, fine motor, gross motor). This practice relies upon principles of child development, with the expectation that skills acquisition typically occurs in a predictable sequence, even though the rate at which individual children learn may vary. For instance, it is generally expected that children will learn to use one or two word sentences before they will progress to three or four word sentences.

Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) – The fourth edition of the reference manual published by the American Psychiatric Association, for which the text was revised in 2000. The DSM-IV-TR appears to be the most widely used manual of diagnostic criteria for autism spectrum disorders in the United States. Under the heading of Pervasive Developmental Disorders, the manual lists and describes Autistic Disorder, Rett’s Disorder, Childhood Disintegrative Disorder, Asperger’s Disorder and Pervasive Developmental Disorder Not Otherwise Specified (including Atypical Autism).

Diphtheria, Pertussis and Tetanus Vaccine (DPT) – An immunization against diphtheria, pertussis and tetanus that is usually given to infants and young children. Research suggests that consideration should be given as to whether or not the pertussis vaccine should be administered to some children, specifically infants with a non-stable neurological disorder, such as seizures, or infants who have had a serious reaction to a prior DPT shot.

Discrete Trial – A method for teaching desired behaviors, skills or tasks. The skill being taught is “broken” down or sequenced into small, “discrete steps” that are taught in a highly structured and hierarchical manner. Discrete trials consist of four parts: (a) the instructor’s presentation (the instruction) (prompt if needed), (b) the child’s response, (c) the consequence, (e.g., reinforcement or correction) and (d) a short pause between the consequence and the next instruction (between-trials interval). The instruction should be clear, concise, phrased as a statement, and given only once.

Early Intervention – Individualized services for infants and toddlers who are at risk for or are showing signs of developmental delay.

Echolalia – The repetition of speech that is produced by others (a relatively common symptom of autism). Echoed words or phrases can include the same words and inflections as were originally heard or they may be somewhat modified. *Immediate echolalia* refers to words immediately repeated or repeated a brief time after they were heard. *Delayed echolalia* refers to the repetition of speech much later – even after days or years.

Environmental modifications – Environmental modifications are not direct instruction, but are therapeutic adaptations that are intended to reduce barriers to instruction.

Epilepsy – Sometimes called a *seizure disorder*. Epilepsy is a condition characterized by recurrent seizures that are caused by abnormal electrical activity in the brain. Seizures can occur for many reasons, including damage to the brain due to infection, injury, birth trauma, tumor, stroke, drug intoxication and chemical imbalance. Epilepsy is usually treated with antiepileptic drugs. It is estimated that about one third of individuals with autism have seizures at some time during their lifetime. *Also see Seizure*.

Experimental (functional) analysis – A type of functional assessment in which the effects of various consequences are experimentally tested on the behavior.

Expressive Language – The ability to communicate thoughts and feelings by gesture, sign language, verbalization, or written word. *Compare to Receptive Language.*

Extended School Year – Special education and related services provided beyond the normal school year, in accordance with the child’s IEP and at no cost to the parents.

Extinction – Eliminating or decreasing a behavior by removing reinforcement from it.

Functional Behavior Analysis– The process of systematically determining the function of behaviors, usually inappropriate, that are displayed by people. Behaviors are defined, measured and analyzed in terms of what happened before and after their occurrence. Over time the events before and after the behavior occurs are systematically changed in order to determine the function of the behavior for the person displaying it. Sometimes an inappropriate behavior can have a communicative function. A temper tantrum can sometimes be communicating “I am upset”, or “I am bored”. Sometimes a functional analysis of behavior is conducted for research purposes, but it can also be performed in order to develop behavior interventions and supports that address the display of challenging or inappropriate behavior. *See Functional Assessment of Behavior.*

Functional Assessment of Behavior – It is similar to the functional analysis of behavior, but it differs in that those events before and after the behavior are not systematically changed in order to prove the function of the behavior. Based on the information gathered a judgment is made about the possible communicative function of the behavior(s). Functional Assessments are usually performed in order to develop behavior interventions and supports that address challenging or inappropriate behaviors. *See Behavioral Assessment and Functional Behavior Analysis.*

Functional intervention – A behavioral intervention that addresses the reinforcer or purpose of a problem behavior.

Generalization – The ability to take a skill learned in one setting, such as the classroom, and use it in another setting like the home or community.

Hand-Over-Hand Guidance – Physically guiding an individual through the movements involved in a fine motor task. Helping someone to grasp a spoon and bring it to his or her mouth is an example of hand-over-hand guidance.

Head Banging – A form of self-stimulation in which the child repetitively bangs head on the floor or another surface. *Refer to Self-Stimulation and Self-Injurious Behavior.*

Hyper- – A prefix meaning above, elevated or excessive. *Compare to Hypo-*.

Hyperactivity – Abnormally increased motor activity, resulting in difficulty with concentrating on one task or sitting still. Due to their overactivity and impulsivity, children who are hyperactive often have difficulty with learning, even if they score in the normal range on IQ tests. Hyperactivity can occur with attention deficit disorder, mental retardation, seizure

disorder, sensory deficit disorders (such as hearing impairment) or other central nervous system damage. Also known as hyperkinetic.

Hypo- – Prefix for under, beneath, down or less than normal. Opposite of Hyper-.

Incidental teaching – Incidental teaching typically involves child-directed activities. The instructor observes and interacts with the child and uses any naturally occurring opportunities to provide relevant instruction (e.g., the child indicates that he wants a drink by pointing to the refrigerator, and the instructor models the correct language).

IEP – The abbreviation for Individualized Education Program. *See Individualized Education Plan.*

IFSP – The abbreviation for Individualized Family Service Plan for children under three years of age. *See Individualized Family Service Plan.*

Inclusion – The general concept of including people with disabilities in all aspects of life, such as (but not limited to) education, community living, employment and recreation. *See Least Restrictive Environment.*

Individualized Education Program (IEP) – A written statement of a child’s current level of development (abilities and impairments) and an individualized plan of instruction, including the goals, the specific services to be received, the people who will carry out the services, the standards and time lines for evaluating progress, and the amount and degree to which the child will participate with non-handicapped peers at school. The IEP is developed by the child’s parents and the professionals who evaluated the child. It is required by the Individuals with Disabilities Education Act (IDEA) for all children in special education, age’s three years and up.

Individualized Family Service Plan (IFSP) – A written plan describing the infant’s current level of development; the family’s strengths and needs related to enhancement of the infant’s or toddler’s development; goals for the infant and the other family members (as applicable), including the criteria, procedures and time lines used to evaluate progress (the IFSP should be evaluated and adjusted at least once a year and reviewed at least every six months); and the specific early intervention services needed to meet the goals (including the frequency and intensity and method of delivering services, the projected date of initiating services and the anticipated duration of services). The IFSP is developed and implemented by the child’s parents and a multidisciplinary early intervention team (IFSP Team). The name of the person responsible for implementation of the IFSP, the case manager, should be listed on the IFSP. If it is likely at age three that the child will require special education services, a transition plan should also be stated in the IFSP. The Individualized Family Service Plan is required by the Individuals with Disabilities Education Act (IDEA) for all infants receiving early intervention services. *Refer to Early Intervention.*

Individuals with Disabilities Education Act (IDEA) – A federal law passed in 1997 that reauthorizes and amends the Education for All Handicapped Children Act (Public Law 94-142). Part C of the law focuses on services to infants and toddlers who are at-risk or have developmental disabilities.

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 appropriate. It is presumed that a child with a disability will be educated in the general education classroom, with appropriate supports, unless the IEP Team deems another setting as more appropriate. LRE is a requirement under the IDEA.

Local Education Agency (LEA) – The agency responsible for providing special educational services on the local (county) level. Also called Local School System (LSS).

Medically Fragile – Referring to an infant or child whose health status either is unstable or renders him at risk for developmental delay, often due to poor health.

Mental Retardation – According to the American Association on Mental Retardation, “Mental retardation refers to substantial limitations in present functioning. It is characterized by significantly subaverage intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure and work.” In other words, someone with mental retardation performs significantly below his age level in both intellectual functioning (intelligence) and adaptive behavior. Mental retardation is the most common developmental disorder, affecting about two to three percent of the total population.

MMR – The abbreviation for Measles, Mumps, and Rubella Vaccine. Thought by some to cause autism in some children.

Motor Skill – The learned ability to perform movements, such as holding the body in an upright position to sit, using the hands to manipulate small items, scooping food onto a spoon and bringing the spoon to the mouth, and moving the lips and tongue to articulate different sounds.

Non-functional intervention – A behavioral intervention that does not directly address the reinforcer or purpose of a problem behavior.

Nonverbal Communication – Any form of or attempt at unspoken or “physical” communication. Examples are temper tantrums, gestures, pointing and leading another person to a desired object.

Occupational Therapy (OT) – Therapeutic treatment aimed at helping the injured, ill or disabled individual to develop and improve self-help skills and adaptive behavior and play. The occupational therapist also addresses the young child’s motor, sensory and postural development with the overall goals of preventing or minimizing the impact of impairment and developmental delay. The therapist also promotes the acquisition of new skills to increase the child or adult’s ability to function independently.

Parent-Professional Partnership – The teaming of parents and teachers, doctors, nurses, therapists and other professionals to work together to facilitate the development of children and adults with special needs.

PDD (Pervasive Developmental Disorder) – See *Pervasive Developmental Disorder*.

Peer-mediated – Using trained single and multiple peers to promote social interaction and academic skills in children with disabilities.

Perseveration – Redundant repetition of word(s) or action(s) without stopping or moving on.

Pervasive Developmental Disorder (PDD) – A diagnostic *category* in the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) that includes Autistic Disorder. The DSM uses the term Pervasive Developmental Disorder to refer to a “severe and pervasive impairment in several areas of development: reciprocal social interaction skills, communication skills, or the presence of stereotyped behavior, interests, and activities.” Sometimes doctors use the abbreviation PDD alone when diagnosing a child who has some, but not all, of the symptoms of autism.

Physical Therapy (PT) – Therapeutic treatment designed to prevent or alleviate movement dysfunction through a program tailored to the individual child. The goal of the program may be to develop muscle strength, range of motion, coordination or endurance; to alleviate pain; or to attain new motor skills. Therapeutic exercise may include passive exercise (in which the therapist moves and stretches the child’s muscles) or the child may actively participate in learning new ways to acquire and control positions and movement.

Picture Exchange Communication System (PECS) – Is a communication training program for helping children with autism acquire functional communication skills. Children using PECS are taught to give a picture of a desired item to a communicative partner in exchange for the item, thus initiating a communicative act for a concrete outcome within a social context.

Pivotal response training – Is a set of procedures designed to increase motivation and promote generalization. It was developed to overcome problems of stimulus overselectivity and motivation. The intervention focuses on a set of specific procedures that increase responsivity to simultaneous multiple cues. The logic of teaching pivotal target behaviors is that educators might indirectly affect a large number of individual behaviors.

Prognosis – An estimate of the course and outcome of a disease or other condition, including the chances of recovery.

Prompt – Input that encourages an individual to perform a movement or activity. A prompt may be verbal, gestural or physical. An example of a prompt is tapping beneath one’s chin as a visual reminder to the child to close her mouth to prevent drooling. Also known as a cue.

Qualitative Developmental Assessment – An evaluation of the quality, rather than the quantity, of a child’s cognitive skills.

Rebus - A Latin word meaning “thing.” A rebus symbol is a picture that visually represents a word or syllable. There are many types of rebuses, but the most common collection was developed as a mechanism for teaching young nondisabled children to read.

Receptive Language – The ability to understand what is being expressed, including verbal and nonverbal communication, such as sign language. *Compare to Expressive Language.*

Regression – Reverting to a more immature form of behavior or decreased skill level. For example, a child who resumes sucking her thumb after a substantial period (months or years) of no thumb-sucking. Regression is usually felt to be an unconscious protective mechanism.

Reinforcement – A behavior modification technique used to increase the likelihood of a desired response or behavior. Positive reinforcement is accomplished by immediately strengthening or rewarding a desirable behavior. The reward can be a social reinforcer, such as praise or a hug, or it can be material, such as a sticker or cookie. One form of negative reinforcement is to withdraw a privilege.

Resource Specialist – A teacher who provides special education instruction to children who are taught by regular classroom teachers for the majority of the school day. Sometimes called resource teachers.

Screening Test or Tool – An evaluation tool designed to identify children who are at-risk for having or developing a developmental disability. This is different from a diagnostic tool that is used to determine if a person has, or does not have, autism.

Seizure – Involuntary physical movement or changes in consciousness or behavior brought on by abnormal bursts of electrical activity in the brain. *See Epilepsy.*

Seizure Disorder – *Refer to Epilepsy.*

Self-Injurious Behavior (SIB) – Abnormal behaviors that are harmful to oneself, such as head-banging or scratching or biting oneself. *See Self-Stimulation.*

Self-Stimulation – Defined as abnormal behaviors that interfere with the individual's ability to pay attention or participate in meaningful activity, such as head banging, watching the fingers wiggle or rocking side to side. It is often referred to as "self-stimming" or "stimming." Unpurposeful play with a toy can be self-stimulating, such as repetitively spinning the wheels of a toy truck instead of exploring the different ways it can be used. In children, self-stimulation is most common when there is a diagnosis of mental retardation, autism or a psychosis.

Sensory Impairment – A problem with receiving information through one or more of the senses (sight, hearing, touch, etc.). For example, deafness is a sensory impairment.

Sensory Integration – The ability of the central nervous system to receive, processes, and learn from sensations in order to develop skills. The sensations include touch, movement, sight, sound, smell and the pull of gravity.

Sensory Stimulation – Any arousal of one or more of the senses. For example, a play activity that includes touching strips of shiny cellophane, listening to them crinkle, and watching while a bright light is shining on them against a contrasting background might be fun and stimulating for a child with visual impairment.

SIB – The abbreviation for self-injurious behavior. *See Self-Injurious Behavior.*

Spectrum Disorder – A disorder, such as autism, that appears with a wide range of characteristics and functioning. At one end of the spectrum of autism individuals tend to have many challenging behaviors. At the other end individuals generally have greater cognitive abilities and can communicate relatively well with spoken language.

Speech Therapy – Therapy to improve the individual's speech and language skills, as well as oral motor abilities.

Stereotypic behavior – Repetitive motor movements that occur frequently; examples include body rocking, hand flapping, and object manipulation.

Stimulus preference assessment – Any systematic method used to predict which stimuli will function as positive reinforcers for a child's behavior.

Strategies – A group of interventions (techniques) that share a common approach.

Task Analysis – Process of breaking a skill down into smaller steps.

Technique – A specific intervention (e.g., reinforcing appropriate behaviors).

Verbal Behavior – A behavioral approach to teaching communication skills to children with autism and other developmental disabilities, based on B.F. Skinner's analysis of verbal behavior.

Appendix I
Parent Support Groups and Resources

Support Groups

Autism Society of America (ASA)

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

Autism Society of America – Maryland Chapters

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

Anne Arundel County ASA

410 923-8800

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

annearundel-asa@maryland-autism.org

Baltimore-Chesapeake ASA

410-655-7933

<http://www.bcc-asa.org/>

baltimorechesapeake-asa@maryland-autism.org

Frederick County ASA

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

frederick-asa@maryland-autism.org

Harford County ASA

harford-asa@maryland-autism.org

Howard County ASA

410-760-5595

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

howard-asa@maryland-autism.org

Montgomery County ASA

301-652-3912

<http://www.autismmontgomerycounty.com/>

montgomery-asa@maryland-autism.org

Prince George's County ASA

princegeorges-asa@maryland-autism.org

Washington County ASA

washington-asa@maryland-autism.org

FIAT (Families for Intensive Autism Treatment)

P.O. Box 341643

Bethesda, MD 20827-1643

301-419-8037

Families of Children with Autism Support group (FOCAS) of Carroll County
(410) 857-1596

Garrett Special Needs Children
(301) 334-2174

Maryland Asperger Advocacy and Support Group
(includes support groups in Southern Maryland, Baltimore County, and Montgomery County)
mdasperger@aol.com
<http://www.aspergers.org>

Howard County Asperger's Syndrome Parent Support Group
(410) 579-2996

Additional Family Resources

Pathfinders Autism Resource Center
120 Allegheny Avenue
Towson, MD 21204
(410) 769-9500
(301) 551-334-2174
1-(866) 806-8400
info@pathfindersforautism.org
<http://www.pathfindersforautism.org>

Maryland Family NET Works
<http://www.family-networks.org/>

The Parents' Place of Maryland
801 Cromwell Park Drive, Suite 103
Hanover, MD 21061
(410) 768-9100
info@ppmd.org
<http://www.ppmd.org>

Maryland Disability Law Center
1800 N. Charles St., 4th floor
Baltimore, Maryland 21201
(410) 727-6352 phone
(800) 233-7201
<http://www.mdlcbalto.org>

Appendix J
The Maryland Autism Medicaid Waiver

The Autism Waiver allows eligible children with autism spectrum disorder to receive necessary waiver services to maintain them in their home and community. To access waiver services, a child must meet all of the following criteria:

Technical Eligibility

- ◆ The child has a diagnosis of Autism Spectrum Disorder as defined in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) as 299.00 Autistic Disorder or 299.80 Pervasive Developmental Disorder Not Otherwise Specified (Including Atypical Autism).
- ◆ The child is between the ages of 1-year-old through the end of the semester that the child turns 21 years old.
- ◆ The child has an Individualized Education Program and is receiving more than 15 hours per week of special education and related services and requires a more intensive therapeutic program than other students, or the child has an Individualized Family Service Plan.
- ◆ The child is able to be served in the community with the assistance of waiver services.
- ◆ The child's parent or legal representative chooses autism waiver services as opposed to ICF-MR services.

Financial Eligibility

- ◆ The child has less than \$2,000 in assets (savings, trust, stock, etc.).
- ◆ The child's monthly income is less than 300% of Supplemental Security Income.

Medical Eligibility

- ◆ The child must meet the minimum requirements in two of three domains on the "Determination of Eligibility for Level of Care in an Intermediate Care Facility for the Mentally Retarded and Persons with Related Conditions (ICF-MR)" form which is completed by a licensed psychologist or certified school psychologist.

Autism Waiver Services Covered by the Waiver

- ◆ Day habilitation, including regular and intensive day habilitation services, intensive individual support services, and therapeutic integration services
- ◆ Residential habilitation
- ◆ Respite care, provided on a short-term basis in the individual's home or place of residence
- ◆ Supported employment
- ◆ Environmental accessibility adaptations, including physical adaptations to the home
- ◆ Family training
- ◆ Service coordination

Autism Waiver Service Providers

Waiver service providers must be Medicaid approved and appropriately licensed or certified.

Benefits

- ◆ Families of waiver participants will be eligible for waiver services that are not currently provided through local school systems, early intervention programs, or the regular state plan Medicaid.
- ◆ Health coverage for the eligible child will be provided through Medical Assistance at no cost to the family.
- ◆ Local school systems, specialized programs, and early intervention programs that become Medicaid providers will be able to seek reimbursement for some of the specialized services for which they are currently unable to bill.
- ◆ Additional children will be Medicaid eligible and receive Medicaid-covered IFSP/IEP services.

Exclusions

Children who are enrolled in Rare and Expensive Case Management (REM) or in any other Medicaid Home and Community-Based Services Waiver such as the Developmental Disabilities Waiver are excluded.

Administration

The Maryland State Department of Education, the local early intervention programs, and the local school systems are responsible for administering the waiver.

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