



Performance Standards

BHRS for Autism Spectrum Disorders

Performance Standards are intended to provide a foundation and serve as a tool to promote continuous quality improvement and progression toward best practice performances, to increase the consistency of service delivery and to improve outcomes for members

Disclaimer: These Performance Standards should not be interpreted as regulations. Entities providing services as part of the HealthChoices program must first be enrolled in the Pennsylvania Medical Assistance program as the appropriate provider type. Providers must then comply with all applicable Pennsylvania laws, including Title 55, General Provisions 1101, licensing program requirements and any contractual agreements made with Community Care Behavioral Health Organization in order to be eligible for payment for services.

BHRS FOR AUTISM SPECTRUM DISORDERS

PERFORMANCE STANDARDS

I. INTRODUCTION

Purpose

These Clinical/Administrative practice guidelines on Autism Spectrum Disorders were developed with the assistance of parents, professionals, and other stakeholders. The guidelines are intended to establish common goals between Community Care, our providers, members, families, and other stakeholders. These are not regulations or limitations on practice or request (s) for medically necessary services. The group of providers, prescribers, and parents who developed these guidelines encourages members to remember that treatment should always be tailored to the individual child. Not all of the recommendations will be appropriate for all situations.

These standards are intended to provide a foundation and serve as a tool to promote continuous quality improvement and progression toward best practice performance, to increase the consistency of service delivery and to improve outcomes for children/adolescents and their families. In some instances, the standards set the bar higher than regulatory requirements. However, these standards reflect the current level of quality within the network and the commitment of all involved stakeholders to continually strive to improve the quality of service delivery to individuals with Autism Spectrum Disorders.

These standards should not be interpreted as regulations, nor will they be utilized as a means of requiring or prohibiting specific interventions for specific individuals. Each child/adolescent receiving behavioral health services requires a uniquely developed treatment plan, which identifies strengths and addresses needs. The group encourages parents and others to seek additional “resource” or “information” guides to assist families in identifying possible options for consideration in choosing evaluation, treatment intervention, and providers. Additional guides to treatment can also help parents assess the outcome of treatment interventions. A recent review of the current literature is also included in this document ([See Addendum IV](#)); however, individuals are encouraged to become familiar with new research findings as they are available.

This document is intended to support the Commonwealth of Pennsylvania’s efforts to improve care for children and adults with Autism. In December 2004, a group of stakeholders met with Estelle Richman, Secretary of the Department of Public Welfare in Pennsylvania, to discuss the concerns regarding the treatment available to children with Autism throughout the Commonwealth. This group made the following recommendations:

- Create an Office of Disability within the Department of Public Welfare that has a Bureau or Division of Autism Spectrum and Related Disorders.
- Create a member-led organization that provides information about Autism services in multiple systems and advocates for the needs of individuals living with Autism.

- Develop an Autism-specific Medicaid Waiver to allow for greater flexibility and creativity in providing services for this population.
- Situate Regional Autism Centers across the state that provide high quality services to individuals with Autism, train professionals in the area to assess and evaluate the needs of people living with Autism, provide education and supports to families, and create opportunities for research to continually improve treatment and supports.
- Develop creative mechanisms for blending and braiding funding between education and Medicaid to ensure coordinated, collaborative care across systems.

Scope

These clinical/administrative guidelines represent a consensus for practices for assessment and interventions for children with Autism Spectrum Disorders (ASD). This guideline is intended to define parameters of “usual” prescriptions and practice for Behavioral Health Rehabilitation Services (BHRS) for children and adolescents with ASD including MT, BSC, and TSS, but is not intended to include RTF, STAP, Day Treatment, and other related programs. It is not intended to limit or constrain prescriptions or services.

In these Best Practice Guidelines, the term “Autism Spectrum Disorder” is widely defined to include the entire range of pervasive developmental disorders that are seen in children and adolescents (from birth up to the age of 21). Autistic Disorder is defined in the current version of the American Psychiatric Association’s Diagnostic and Statistical Manual (DSM-IV-TR) as:

- A. A total of 6 (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 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.

These guidelines will focus on the diagnosis of Autistic Disorder, as well as the associated disorders of: Asperger's Disorder, Rett's Disorder, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder, NOS listed in the DSM-IV-TR.

II. Service Description

While this document is focused on standards for delivery of BHRS for children and adolescents with ASD, these same individuals are often authorized to receive a variety of behavioral health services throughout the service continuum. While only a percentage of children with ASD are receiving these services, there is an opportunity to enhance treatment outcomes when these levels of care are utilized judiciously. This may be particularly important with children who are in families that may themselves be disrupted because of the stress of managing the child's special needs, or because of other social and environmental factors that may be essentially unrelated to such needs. Along with BHRS, which is described fully in this document, common additional components of this service array (ordered most restrictive to least restrictive) include:

- **Inpatient Mental Health Hospitalization** Inpatient units provide a secure/locked setting for the delivery of acute care services for children/adolescents with an ASD, additional serious mental illness, or co-occurring disorders, e.g., MR, D&A. Such acute care requires coordinated, intensive, and comprehensive treatment, tailored to the individual member's immediate status and needs for the purposes of continued recovery.
- **Residential Treatment Facilities (RTF)** This level of care includes both facilities that are accredited by the Joint Commission on the Accreditation of HealthCare Facilities (JCAHO) and those that are licensed and supervised by the Department of Public Welfare but are not JCAHO accredited. These are structured treatment facilities. Although the length of stay is determined by medical need, the average length of stay ranges from four to eight months. RTF services are not typically "first line" services invoked for the treatment of children with ASD. Typically, use of this

level of care might indicate significant behavioral problems that cannot be managed in a less restrictive treatment environment.

- **IRT/CRR Host Home/Therapeutic Foster Care** IRT provides a 24 hour/day safe, structured environment within a family setting (Host Home) including intensive community based treatment to support the child/adolescent's efforts to meet basic needs, utilize appropriate judgment, coping skills, and comply with treatment. This is an unlocked, less restrictive, and more flexible alternative than inpatient or RTF for the delivery of acute care and for provision of transitional care from an inpatient or RTF setting.
- **Behavioral Health Rehabilitation Services (BHRS)** See further description below.
- **Family Based Mental Health Services (FBMHS)** FBMHS for children and adolescents are team delivered services rendered in the home and community which are designed to integrate mental health treatment, family support services, and case management, so that families may continue to care for their children/adolescents with serious mental illnesses or emotional disturbances at home. FBMHS are intended to reduce the need for psychiatric hospitalizations and out-of-home placements by providing services that enable families to maintain their role as the primary caregiver for their children/adolescents. While FBMHS are utilized less frequently for children with ASD, such individuals may be eligible for these services when they are determined to be at high risk for out-of-home placement and involved with multiple systems.
- **Partial Hospital Services** This level of care provides a less restrictive, more flexible setting than inpatient hospitalization for the delivery of acute care. It is often used to transition members out of acute care or serves as an alternative. The primary functions of partial hospitalization services include providing support to help the member manage the safety of himself/herself, others, and property, to reduce acute and chronic symptoms, to evaluate and manage medication therapies, to help the child and family build a variety of skills that strengthen the child's ability to function independently, and to develop an aftercare plan for less restrictive, less intrusive services.
- **School Based Partial Hospital Programs (SBPH)** SBPH provides licensed mental health partial hospital services for select children/adolescents with serious emotional and mental health needs. These programs can take place in an approved private school and/or an alternative setting such as an outpatient provider. Placement in such settings is normally initiated by the student's home school district when the district can no longer effectively meet the student's educational needs within the district's programs. Students in SBPH programs have an Individualized Educational Plan (IEP) as well as formal mental health treatment plans covering the range of strengths, needs, and goals of the programs.
- **Outpatient services** These types of services include a range of short term and long term treatments which vary with the child's diagnosis, severity of illness, coping skills, and available support systems. Outpatient treatment may include medication evaluations, medication management, individual therapy, family therapy, group therapy, and may include treatments such as positive behavior support, social skills, cognitive based interventions, and communication. Group therapy may be particularly beneficial for children/adolescents with ASD when the focus of the group

is to enhance communication and social skill development. While the range of Autism specific outpatient programs differs widely in different geographic areas, the development of such programs continues to be a focus of many providers statewide.

- **Case Management Services** This type of service (which is only available in some counties) assists members and families with service coordination, linkage to resources or other needed services and mental health advocacy. When receiving BHR services, a member can also receive case management services through their BHRS provider. The case manager in BHRS is responsible for coordinating care between providers, identifying community supports, helping to link members to alternative services, scheduling appropriate ISPT meetings and organizing/managing packet information required by the Managed Care Organizations.
- **Resource Coordinator (RC)** This individual helps to link families to services, identify appropriate supports/resources including both mental health and educational settings, can aid in transportation to and from medical/psychiatric appointments, and identify community supports.
- **Intensive Case Manager (ICM)** An ICM is very similar to an RC and can link families to services, identify appropriate supports/resources including both mental health and educational settings, can aid in transportation to and from medical/psychiatric appointments and identify community supports as well as medication monitoring/compliance. Children involved with an ICM have access to 24 hour on-call ICMs to assist in a mental health crisis.
- **Crisis Services** These services may be accessed through a medical or psychiatric hospital emergency room, crisis center, or via a mobile crisis team. A mobile crisis team provides individual or team delivered intervention in the member's home, school, work, or community to address the crisis situation. Regardless of the method of crisis intervention, the main goal of crisis services is to establish safety, provide stabilization, and divert hospitalization when possible.

Detailed Service Description for BHRS

Behavioral Health Rehabilitation Services (BHRS) BHR services include a range of primarily individualized behavior management treatment and rehabilitation services provided in community settings. Settings typically include the child's home and or school as well as other settings such as camps, recreational venues, or commercial establishments. These services are most widely utilized in the treatment of children with ASD. BHRS treatment consists of services delivered as medically necessary by one or more of the following professionals:

Behavior Specialist Consultants (BSC) BSC are staff at the master's or doctoral level who assess and analyze behavioral data, develop child specific treatment plans and consult with the treatment team concerning the implementation of the treatment and behavioral plans. Once authorized by the Managed Care Organization, BSC services can begin in the home without a Therapeutic Staff Support (TSS) for the purpose of completing a functional assessment, writing a detailed treatment plan, and conducting family education. Although this is not a requirement, the BSC may also supervise and

train BHRS staff working with children with ASD. Recommended training and experience for BSC professionals serving individuals with ASD must meet the following requirements prior to working with families include A, B, and C below:

A. Degree:

- Doctoral degree in an approved related field
- Licensed psychologist, or
- Master's degree in a related field
- Extensive knowledge of principles of positive behavior support, as evidenced by:
 - Certification in applied behavior analysis (ABA) or other national certification associated with behavioral management.
 - A minimum of 12 graduate level credit hours in course work related to behavioral management theory, interventions, protocols, or techniques.
 - Prior training on basic positive behavior support principles, ongoing participation in ABA related courses, as well as concurrent supervision and guided practice under a staff member meeting criteria A or B.
 - At least one year experience practicing positive behavioral support interventions while providing clinically supervised treatment to children/adolescents.

B. Training:

- 10 hours of training on basic principles of behavioral health services before working with families, to include:
 - Ethics; including confidentiality.
 - Documentation.
 - Behavior management.
 - Boundaries.
 - Mandated reporting.
 - Consultation skills including the transfer of skills to families, schools, and natural/community resources.
 - Family systems.
 - CASSP principles.
 - Crisis intervention.
 - Involving families, schools, and the community in the child's treatment.
- A minimum of 10 hours of training on basic principles of Autism, to include:
 - Characteristics, diagnoses, and therapeutic approaches specific to ASD.
 - Building rapport with children (and families).
 - Typical child development.
 - Communication.
 - Sensory integration.
 - Teaching social skills.
 - Play skills.
 - Constructing behavior and treatment plans utilizing positive intervention strategies for behaviors.

C. Supervision

- A BSC with no prior experience treating children with ASD should have a minimum of five hours of on-site supervision on his/her first assigned case for a child with Autism. A new BSC may also require increased supervision over the first six months

of employment at the discretion of the clinical supervisor.

- A minimum of monthly clinical supervision by senior clinical staff, certified behavioral analyst, licensed psychologist, psychiatrist, consultant, or Autism coordinator.

Continued Training:

- All training must be documented in the agency training log.
- The fulltime BSC must complete 24 hours of continued training per year (total training) that includes specific training in the area of Autism. A part time BSC must complete continued training proportionate to fulltime employment with a minimum of six hours per year.
- Professional development in the area of Autism may include, but is not limited to:
 - Communication Skills, e.g., visual strategies, verbal behavior, PECS.
 - Social Skills, e.g., social stories, Floortime, comic strip conversations, relationship development intervention (RDI).
 - ABA, e.g., Positive Behavioral Support, Discrete Trial, and behavioral management techniques.
 - Sensory Issues, e.g., sensory integration.
 - Inclusion.
 - Sleep Disorders.
 - Eating Concerns/Functional Feeding.
 - Skills Acquisition Techniques, e.g., precision teaching.
 - Alternative Interventions, e.g., nutrition, vision therapy, auditory integration.
 - Training on Autism and Co-existing disorders, e.g., medications.
 - Related Assessments/Data Collection.

Mobile Therapists (MT) MT are staff at the master's or doctoral level who provide intensive individual or family therapy services to children with ASD and their families in settings other than a provider agency or office. Settings may include the child's home, the school, the church, the community center, a neighbor's or extended family member's home, and other community settings. Provision of child-centered, family-focused, individual and family psychotherapy, as defined in the treatment plan and agreed upon by the therapist and family, may utilize a number of formats which may vary according to the individualized needs of the child. Psychotherapy in the home or community setting may include sessions with:

- The child individually.
- The entire nuclear family.
- The family and a community resource – minister, scoutmaster, community leader, mentor, other.
- The family and teacher, guidance counselor, or principal.
- Subsystems of any of the above, as clinically indicated, agreed upon and identified in the treatment plan.
- The client's sibling if sibling issues are directly related to the client's behaviors and/or diagnosis.

MT services may commence prior to the start of TSS services for the purpose of grief counseling, family support, and family education. These services are

particularly beneficial when specialized therapeutic interventions are utilized to assist clients in developing more effective emotional regulation, crisis planning, social skills, communication skills, and improved peer relationships. Recommended training and experience for MTs serving individuals with ASD is as follows:

A. Degree:

- A Licensed mental health professional.
- An individual with a master's degree in a related field and at least one year experience in a CASSP system (employed by or under contract to Children and Youth Services, Juvenile Justice, Mental Health, Mental Retardation and/or Early Intervention, Special Education, or Drug and Alcohol working with children).
- Training and Experience: A combination of training and experience in a range of therapeutic modalities appropriate for children with ASD and their families, including:
 - Family therapy and systems.
 - Play therapy, direct and indirect.
 - Grief and loss.
 - Cognitive Behavioral Interventions.

B. Training:

- 10 hours of training on basic principles of behavioral health services before working with families, to include:
 - Ethics; including confidentiality.
 - Documentation.
 - Behavior management.
 - Boundaries.
 - Mandated reporting.
 - Consultation skills including the transfer of skills to families, schools, and natural/community resources.
 - Family systems.
 - CASSP principles.
 - Crisis intervention.
 - Involving families, schools, and the community in the child's treatment.
- 10 hours of additional training on basic principles of Autism, to include:
 - Knowledge of principles of Positive Behavior Support, OR ongoing participation in ABA related courses, OR concurrent supervision and guided practice under a staff member with qualifications equivalent to the BSC as listed above.
 - Characteristics, diagnoses, and therapeutic approaches specific to ASD.
 - Building rapport with children.
 - Typical child development and developmental differences characteristic of Autism.
 - Communication.
 - Sensory issues.
 - Teaching social skills.
 - Play skills.

C. Supervision:

- An MT with no prior experience providing clinical treatment to children with ASD

should have increased supervision and consultation, which may include mentoring and shadowing, during the first six months of employment.

- MTs who have the appropriate experience OTHERWISE will require a minimum of monthly clinical supervision by senior clinical staff with the same degree or higher including but not limited to: certified behavioral analyst, licensed psychologist, psychiatrist, consultant, or Autism coordinator.

Continued Training: In addition, continuing professional development should include but not be limited to attendance at ongoing trainings related to Autism for a minimum of 24 hours per year on topics such as:

- Communication.
- Family systems.
- Emotional Regulation.
- Social Stories.
- Anger-monitors.
- Relaxation Training.
- Coping Strategies.
- Comic strip conversations.
- Grief and Loss.
- Building Independence/self-sufficiency skills.
- Social Skills.
- Positive Behavioral Support.
- Sensory Issues.
- Inclusion.
- Sleep Disorders.
- Eating Concerns/Functional Feeding.
- Skills Acquisition Techniques.
- Alternative Interventions.
- Systematic Desensitization.
- Multimodality/sensory therapy.
- Family and sibling interventions.
- Asperger-specific interventions.
- Social Stories.
- Floortime/DIR.
- Visual strategies.
- PECS.
- ABA.
- Verbal Behavior.
- Discrete Trials Training.

In addition, while not currently reimbursable within BHRS, utilization of the services of an Autism Coordinator may be useful but is at the discretion of each provider, to provide specialized training, oversight, and related services to the treatment team.

Recommended training and expertise for the Autism Coordinator is as follows:

- Master's degree in a related field, with a minimum of three years experience in professional work with children with ASD or bachelor's degree in a related field, with a minimum of five years experience in professional work with children with ASD. For bachelor's level Autism Coordinators, the primary function would most appropriately involve case management rather than extensive clinical oversight.
- Extensive knowledge of principles of ABA, as evidenced by:
 - Certification in ABA.
 - A minimum of 12 graduate level credit hours in course work related to behavioral management theory, interventions, protocols, or techniques.
 - Prior training on basic ABA principles, ongoing participation in ABA related courses, as well as concurrent supervision and guided practice under a staff member with qualifications equivalent to the BSC as listed above.
 - 10 hours of training on basic principles before working with families, to include:
 - Confidentiality.
 - Documentation.
 - Behavior management.
 - Crisis intervention.
 - Involving families in the child's treatment.
 - Expanded knowledge of a range of related therapeutic/treatment methodologies, such as:
 - Visual strategies.
 - PECS.
 - Augmentative communication.
 - TEACCH.
 - Social stories.
 - Comic strip conversations.
 - Verbal Behavior.
 - Floortime.
 - Discrete Trials Training.
 - Attendance at ongoing trainings related to Autism for a minimum of 24 hours per year.
 - Supervision by and consultation with senior clinical staff.

Therapeutic Staff Support (TSS) TSS are staff that provide direct services to clients with ASD under the supervision of a master's level clinician (typically the BSC or MT). TSS workers implement interventions defined in the treatment plan. Generally, these staff members are educated at the bachelor's degree level and have at least one year of applicable experience in human service fields as providers of care.

Recommended training and experience for TSS workers serving individuals with ASD is as follows:

- Persons with a bachelor's degree in psychology, social work, counseling, or sociology.
- Education, criminal justice, or similar human service field, with no previous work

experience.

- Persons with a bachelor's degree in any other field, with the equivalent of at least one year of fulltime paid work experience in a job that involved direct contact with children/adolescents.
- Licensed registered nurses, with the equivalent of at least one year of fulltime paid work experience in a job that involved direct contact with children/adolescents.
- Persons with an associate's degree or 60 credits toward a bachelor's degree, with the equivalent of at least three years of fulltime paid work experience in a job that involved direct contact with children/adolescents.
- Licensed practical nurses, with the equivalent of at least three years of fulltime paid work experience in a job that involved direct contact with children/adolescents.

Training for Inexperienced TSS Workers

Persons who have no TSS experience must complete the following training, which must be documented in the agency's file:

- Prior to working alone with children or adolescents, no fewer than 15 hours of training, some of which includes a specific focus on Autism.
- Within the first six months of working with children and adolescents, no less than an additional 24 hours of training, some of which includes a specific focus on Autism.

The overall training curriculum must include at least the following topics:

- Professional ethics, conduct, and legal issues, including child protective services and mandated reporting, and confidentiality.
- Understanding CASSP principles and implementing and supporting those principles in actual clinical practice.
- The role of the TSS worker in the home, school, and community, including the use of community resources to support the child/adolescent/family.
- Crisis intervention, behavior management, and safety.
- Overview of serious emotional disturbance and other behavioral needs in children and adolescents (with particular emphasis on the specific diagnoses of the children/adolescents with whom the TSS staff may be working).
- Collaboration with families.
- Normal child/adolescent development.
- Behavior management skills.
- CPR, first aid, universal precautions, and safety.
- Documentation skills.
- Psychotropic medications, including common side effects.

Training for Experienced TSS Workers

All TSS workers are encouraged to receive at least 20 hours of training each year after the first year of fulltime or part-time employment as a TSS worker, to acquire additional knowledge of and skills in delivering TSS services. All training should be documented in the agency's file, and should include specific Autism training.

Suggested Assessment and Assistance for All TSS Workers

Three hours for TSS with more than six months of TSS employment; six hours for TSS with less than six months TSS experience

A TSS with no prior experience treating children with ASD should have a minimum of five to 10 hours of observation, supervision, and consultation by the BSC, which may include mentoring and shadowing, during the first six months of employment.

In addition, continuing professional development should include:

- Attendance at ongoing trainings related to Autism for a minimum of 24 hours per year on topics including but not limited to: (Note: “1” designates recommended initial training; “2” designates recommended training within the first six months)
 - Building rapport with children and families (1).
 - Boundaries (1).
 - Strengths Based Philosophy specific to ASD (1).
 - Sensory integration (2).
 - Play skills (2).
 - Overview of ASD (1).
 - Basic Principles of Applied Behavioral Analysis (ABA) (1).
 - Social Stories (2).
 - Visual strategies (1).
 - PECS (2).
 - Structured Teaching/TEACCH (2).
 - Verbal Behavior (2).
 - Floortime (2).
 - Discrete Trials Training (1 or 2 as per program orientation).
 - Communication (1 and 2).
 - Family systems (2).
 - Emotional Regulation (2).
 - Anger-monitors (2).
 - Relaxation Training (2).
 - Coping Strategies (2).
 - Comic strip conversations (2).
 - Grief and Loss (1 and 2).
 - Building Independence/self-sufficiency skills (1 and 2).
 - Social Skills (1 and 2).
 - Positive Behavioral Support (1).
 - Inclusion (2).
 - Sleep Disorders (2).
 - Eating Concerns/Functional Feeding (2).
 - Skills Acquisition Techniques (1).
 - Alternative Interventions (1).
 - Systematic Desensitization (2).

TSS Supervision

- TSS with less than 20 hours of direct service per week will receive weekly supervision for a minimum of 30 minutes.
- TSS with 20 or more hours of direct service per week will receive weekly supervision for a minimum of one hour.

III. Referral Process

BHRS providers serving individuals with ASD should continually educate referral sources about the service, program strengths, methodologies used, and the appropriateness of referrals based on state guidelines and Medical Necessity Criteria. Referral sources are expected to provide sufficient information to the BHRS providers in order for providers to manage referrals appropriately and to have adequate staff to provide for anticipated needs.

Prescribers and providers should inform families and referral sources that there is a choice of providers and that the service is voluntary. The prescriber and provider has an obligation to provide information to the family to ensure that the family has the opportunity to make an informed choice about their provider, and with the knowledge that they can obtain services with another provider in the future if desired. Providers are expected to respond rapidly to referrals, with the scheduling of an evaluation within seven days of the original request for services. At the completion of the evaluation recommending BHRS, the provider is expected to initiate the prescribed services within 50 calendar days.

If a provider is unable to offer timely access to services, the provider is expected to inform the family, and the family may choose another provider. If the family chooses to wait for services, documentation is necessary. If a family wants immediate access to services they should be directed to contact their MH/MR case manager or Community Care to assist them in obtaining an evaluation and BHRS. Providers are also expected to notify Community Care, the family and/or case manager when unable to meet timely access standards.

BHRS providers must demonstrate reasonable efforts to engage both clients and their families in the treatment process. Efforts should be documented and should include multiple types of interventions such as telephone contact, letters, and as stated previously, contact with the referral source.

BHRS providers should follow all HIPAA regulations specific to releases of information, including informed consent of the members and families.

Upon initial contact with families, the BHRS provider is expected to discuss confidentiality issues with the member (when age appropriate) and family to obtain written permission to consult with others that will aid in the assessment, treatment plan development, and monitoring of the effectiveness of treatment interventions

over the course of care.

BHRS treatment teams should assist families in identifying all resources within their natural support system to help empower the clients and families.

Upon the initial intake contact, the provider should be prepared to review with families the role of BHRS as well as the agency's specific areas of knowledge and methodologies, as related to the individual child's needs. In cases where the family's choice of methodology or treatment approach is beyond the scope of the provider, the provider will make an appropriate referral.

Families should be given BHRS service descriptions, such as a parent handbook, outlining agency policies and procedures relevant to their child's service. During initial contacts, providers are expected to clearly discuss with families what can be expected from the services and the expectation of the family as the head of the treatment team.

IV. Admission Process

Children/adolescents who receive BHRS must meet the Medical Necessity Criteria established by the Department of Public Welfare (DPW) and per Appendix T Part B (2) guidelines for BHRS.

BHRS is intended to be comprehensive and intensive, and therefore, individuals with ASD as well as their caregivers must be willing to commit a considerable amount of time and effort to participate in the services. The model is most effective when caregivers believe that they share responsibility with other interagency team members for supporting their child to meet the goals the family and team have worked together to develop.

For an individual to access BHRS, a Pennsylvania-licensed psychologist, psychiatrist, or developmental pediatrician must prescribe the service as medically necessary prior to the initiation of services. The Best Practice Psychological Evaluation should be completed in Life Domain format, as outlined in *Best Practice in Child and Adolescent Mental Health Services* by the DPW Office of Mental Health, Bureau of Children's Services ([see Addendum I](#)). This format is recommended to ensure a comprehensive evaluation of the child/adolescent and family's strengths and needs, review of past treatment trials, and full consideration of the continuum of care available to children/adolescents. In addition, this evaluation will optimally comment on the cognitive/developmental and adaptive skill level for the ASD child as per evaluations completed by behavioral health and other systems, e.g., education, medical, early intervention, and MR. The Best Practice Evaluation must include adequate screening for co-occurring disorders, including MISA screening, if applicable.

In addition to professional licensure, the prescriber should have:

- Knowledge of child development and direct clinical experiences with Autism and other developmental disabilities.

- An understanding of and/or the ability to determine the cognitive/developmental and adaptive skill level for ASD children.
- Working knowledge and utilization of standardized measurements specific to the assessment and diagnosis of children with ASD ([see list in Addendum II](#)).
- Direct knowledge and understanding of types of services available and their application in specific clinical pictures.
- Knowledge of CASSP Principles and incorporation of these into the assessment process (the evaluation itself should reflect that these principles have formed the underpinnings of the evaluation).
- Knowledge of available professional levels of care and ability to refer appropriately as needed.
- Knowledge of the resources in the community (agencies, support groups, community programs, etc.).

Since the evaluation is for the purpose of assessing clinical need and recommending home or community based services, it is expected that the parent/caregiver and child be involved in the evaluation. In addition, relationships between the child and the following individuals should be discussed in the evaluation as well as the absence of any of these relationships:

- Parents/caregivers.
- Child.
- Teachers.
- Siblings.
- Past and current providers.
- Significant Others.
- Direct Care staff.

BHRS evaluations should:

- Attempt to be conducted in an environment which appropriately meets the child's needs, e.g., with attention to possible sensory issues, fears, perseverations, and potential reinforcers.
- Focus on the child's presenting problems.
- Include strength based interviews and reports that identify competencies and resources as well as needs.
- Be individualized.
- Include parent/caregivers' observations of their child's skills and behaviors.
- Include measurable data (frequency, intensity, and duration), as provided by staff and family/caregivers.
- Address cultural and family context in assessing need.
 - Incorporate results of at least one standardized measurement appropriate to the child's diagnosis, to assess baseline symptoms (initial evaluation) and progress/change (re-evaluations).
- Note child's nature of relating to the evaluator, for example, the child's behavior and whether comfort level with the evaluator decreases or increases over time.
- Note the nature of the child's relating to parents/caregivers.
- Assess and document communication skills that are presented at the interview.

- Include a review of previous treatment modalities and interventions as well as outcomes.
- The initial evaluation should include one or more diagnostic measures ([see Addendum II](#)).

Subsequent re-evaluations should include a comprehensive review of treatment outcomes, as measured by a standardized instrument ([see Addendum II](#)).

V. Treatment Planning Process

BHRS providers should utilize interagency service planning team meetings as a tool to ensure coordination of care for children/adolescents and families. Providers must convene, at a minimum, prior to the initiation of services, at the end of the first and second 9-week treatment periods, and every 4 months thereafter. The treatment plan should be reviewed monthly, and additional formal interagency service planning team (ISPT) meetings should be used more frequently if clinically indicated.

Providers are responsible for ensuring that the core components of the ISPT meeting process are addressed including:

- All involved agencies, systems, natural supports, and community resources that the family wishes to include in the meeting are formally invited to participate and clearly notified in advance of the meeting of the location and time. Meetings are scheduled at the family's convenience both in terms of time and location, with consideration given to promoting attendance by key members of the interagency team.
- The BHRS team should discuss the ISPT meeting process with the family prior to the meeting, defining goals and ground rules for the meeting, as well as determining with the family who will facilitate the meeting and how the team can be most supportive of the family during the meeting. The roles of each of the participating BHRS staff in the ISPT meeting should be clearly defined prior to the meeting. The family has the right to identify issues that are off limits for discussion in the ISPT meeting. The ISPT meeting process can be used to support families in the development of self-advocacy skills.
- The ISPT meeting should follow a standardized agenda that addresses referral concerns, and strengths and needs of the child/adolescent and family. The agenda should support the family to talk early in the process and to outline their hopes for their child. The development of treatment goals and/or progress on goals should be addressed. Modifications to the standardized agenda should be made to accommodate the unique needs or characteristics of families.
- The ISPT meeting is an opportunity for all involved systems and the family to develop and/or discuss treatment goals across systems and ensure that goals defined by various involved systems are as integrated as possible and do not conflict. The meeting also establishes accountability of all those involved in assisting the child to meet his or her goals.
- ISPT meetings should include a discussion of both formal and informal supports. Linkages to supports in a variety of settings including home, school, community,

mental health, social/recreational, and other systems should be explored for all family members. There should be significant exploration of natural and informal supports as well. The ISPT meeting presents an opportunity for the team to identify any obstacles to obtaining resources for the family.

- Meeting participation is documented with the ISPT meeting sign-in form. A treatment plan is generated following the discussions which occur at this meeting.
- Development of the Treatment Plan: BHRS providers are expected to create a service delivery environment in which children/adolescents and their families participate as full partners of the treatment team in the development of treatment plans.

The service planning process is expected to identify initial priorities for services and establish a progressive course for treatment. The team should make an immediate safety risk assessment. This plan should include a crisis/safety plan for the child and family. The treatment plan should function as a living, usable document. It should be used as a working map for what the team and family plan to achieve and how to accomplish those goals. The plan should present a comprehensive perspective of child/family functioning.

The treatment plan is to be developed in collaboration with the family and reviewed with the family at least every 30 days. The treatment plan document serves as a “contract” between all involved parties regarding their responsibilities for the services to be rendered to the identified child/adolescent and their family. Monthly family reviews provide the opportunity to test that the treatment plan continues to be meaningful to the family and that the goals are realistic and achievable. Rating progress weekly can also be very useful in reviewing the effectiveness of current interventions and making modifications when clinically necessary. When progress is minimal, the BHRS team should seek supervisory input.

With the member and/or family’s consent, all members of the ISPT should receive copies of those parts of the treatment plan relevant to their involvement with the member. With the permission of the family/guardian, the plan should be shared with the school, when appropriate, to ensure that behavioral interventions are consistent across all environments. The member and/or family should sign the treatment plan and receive a copy of the document.

The service planning process and the resulting treatment plan should address the strengths and needs of each family member and clearly define goals, objectives, and interventions. The objectives need to reflect observable and measurable steps in the client’s progress to achieving the stated goals. Target dates for the completion of goals need to be realistic and projected for each goal. Establishing target dates is an effective way of anticipating the length of stay at this level of care.

Goals must be related to identified behavioral concerns, and must be achievable and measurable. Goals must have realistic, practical meaning for families, so that the family’s active participation can be facilitated. Treatment plans are expected to be written in words that are understandable to families, to allow the parents to observe,

acquire, and practice necessary skills to function independently when BHRS is tapered and eventually discontinued. Goals must be written to insure consistency for the family to implement in the absence of BHRS staff. Having measurable goals to review with families also helps families to recognize their progress and therefore their readiness for discharge. Unnecessary behavioral health professional jargon should be avoided.

The treatment plan should identify how services from several sources will be coordinated and integrated to best address the needs of the child/adolescent and family. When multiple systems are involved, the BHRS team should discuss with the family the need for regularly scheduled ISPT meetings. The BHRS team is responsible for convening such meetings as frequently as necessary to ensure well-coordinated service delivery.

Establishing the primary goals for services is often difficult given the complex needs of children/adolescents in need of this level of care. A deliberate discussion of overall goals and the narrowing to priority goals is an important step in the treatment planning process. BHRS teams should assist families in helping to focus on a reasonable number of meaningful, attainable goals for each 4 month treatment period. Treatment plans should reflect building support systems and community linkages. BHRS are always to be aimed at building family self-sufficiency and healthy interdependency.

An emergency/crisis/safety plan may be a necessary part of the treatment plan. This must be explored at each ISPT meeting. In instances where no such plan is needed, the treatment plan should include adequate documentation that this topic was discussed.

The treatment planning process must include a discussion with the family to identify discharge goals and to prepare for the transitioning out of BHRS. While this may be difficult at times, it is essential that BHRS providers commit to discussing discharge planning from the beginning of treatment and at each subsequent ISPT meeting. The provider has a professional responsibility in guiding the family to determine realistic discharge criteria.

Progress notes should be connected to the treatment plan and all activities and interventions of the BHRS staff must be related to the goals of treatment.

The treatment team is expected to review the implementation of the treatment plan on a case-by-case level in supervision, evaluating the effectiveness of interventions and discussing implementation of interventions in the context of supervision.

- Appropriate plan (items to include in the treatment plan):
 - Detailed behavior plan (targeting specific behaviors to be addressed by the interventions)
 - Information regarding transfer of skills to caregivers and other natural supports.
 - A specific list of services to be provided and where.
 - Documentation of integration with other services such as special education or other treatment.

- Identification of behavioral bench marks to chart progress.
 - Identification of data collection method.
 - Task List.
 - Scheduled on-going analysis.
 - Plan for transitioning to another level of service or supports.
- Frequency, intensity, and duration of intervention:
 - Recommendations for child will be based on child's individual needs.
 - Parents should be active participants in all aspects of treatment.
 - The duration and intensity of treatment will vary widely. Considerations should include age, severity of Autism, family participation, rate of progress, other health considerations, additional levels of services, and community activities in which the child is involved.

Service Delivery:

In collaboration with the family, the provider should determine the time and location where behavioral intervention is clinically needed. The provision of services should be scheduled in such a way that is consistent with these needs.

BHRS for children with ASD is designed as a comprehensive and intensive service with the primary goal of maximizing the child and family's independent functioning, by facilitating the development of the child's social and communication skills, as well as self-regulation of atypical behaviors. In addition to early assessment and treatment planning activities, a primary goal of early contacts with the families is to engage families fully in treatment.

The treatment plan is to guide service delivery. Services rendered are to support attainment of the identified goals. Documentation of service provision must clearly demonstrate the interventions provided, the response to the interventions, the relatedness to the treatment plan, and progress toward goal attainment. A narrative description of the treatment session alone is not adequate documentation.

Documentation of services provided should note the modality of treatment, the participants, the primary focus of the session, and identification of key interventions delivered in a detailed manner. The role of each of the team members working with any given family should be clearly identified within the team, with the family, and reflected on the treatment plan.

The assessment of the child/adolescent's needs and the treatment plan should be used as a guide in determining the intensity of service delivery. Individual work can be done with other family members as long as it is directly related to the identified member's treatment goals.

Recommended Behavioral Health Treatment Modalities and Interventions

I. Applied Behavioral Analysis

Behavioral interventions are prominent interventions for treating children and adults with Autism. In recent years several intensive intervention programs for children with Autism have been developed. These are based on a systematic behavioral approach. The approach is often known as Applied Behavior Analysis (ABA). ABA is not a treatment in and of itself; rather, it is a category of interventions. This segment of the practice guidelines discusses the group's agreement on the scope of ABA, what it should look like in a treatment plan, professional competencies, and the appropriate recipients.

It is recommended that the principles of ABA and behavior intervention strategies be included as an important element of any intervention program for children with Autism and that one or more of these ABA interventions may be used to treat an individual with ASD. Although there are many specific interventions available for the treatment of ASD, the 7 dimensions of ABA include:

- **APPLIED:** ABA focuses on the implementation of basic principles, i.e., reinforcement, punishment, extinction, stimulus control, establishing operations, contingencies, functional relations, generalization to behaviors of significance to the participants involved.
- **BEHAVIORAL:** ABA focuses on behavior in its own right as a target for change.
- **ANALYTIC:** ABA seeks to identify functional relations between behavior and environmental events through scientific study.
- **TECHNOLOGICAL:** In ABA, procedures are completely and precisely defined.
- **CONCEPTUALLY SYSTEMATIC:** In ABA, procedures are linked to, and described in terms of, the basic principles of behavior.
- **EFFECTIVE:** In ABA, the changes in behavior are significant to the participants involved, cost effective, and efficient. Behavior analysts attempt to use procedures that promote generalization and maintenance of behavior change.
- **GENERAL:** Behavior analysts attempt to discover procedures that can be applied effectively to many individuals and in many settings. (BCBA Task List, 2nd edition, March 1997).

Staff providing behavioral intervention should receive regular supervision from a qualified professional with specific expertise in ABA.

Discrete Trial Therapy

Discrete Trial Therapy is one method of intervention within the broader category of ABA. In this method, behavioral goals are defined through a series of very specific steps or programs that are based on the typical development of a child. Each step is broken down into smaller sub-skills that may be individually taught. For example some of the widely known models of Discrete Trial Therapy include, but are not limited to, UCLA/Lovaas, McEachin, Princeton and Rutgers.

Discrete Trial Therapy is a very specific format of instruction for building a foundation to gain skill acquisition. This model teaches the child to "learn how to learn". Specific

instruction is given to produce a specific response with the overall goal of generalization of the skill to different persons, commands, and domains. Teaching in discrete trials breaks down instruction into antecedent (discriminative stimulus – SD), behavior (response – R), and consequence (reinforcing stimulus – SR).

Discrete Trial Therapy is preferable for children at the early stages of intervention and/or younger children as most research has supported this method for children between 2 and 6 years old. Requisite skills are taught in this type of therapy including, but not limited to, compliance, attending, pointing, and imitation.

Training standards: In addition to the training standards indicated in this document, the BSC must have specific training in Discrete Trial Therapy to implement this type of treatment. At minimum, the BSC should have foundation knowledge in one of the comprehensive Discrete Trial Therapy approaches. For TSS with no prior experience working with this model, the requirements are a minimum of one full day of in-service training, as well as a minimum of six to 10 hours of one-to-one guided practice for the specific child with whom the TSS will be working.

Analysis of Verbal Behavior

Analysis of Verbal Behavior is a form of ABA with a focus on Skinner's analysis of verbal behavior. It applies the science of behavior analysis to teaching verbal behavior. In this program, goals are addressed based on the child's ability to communicate or use basic verbal behaviors, e.g., learning to request wants and needs. Skinner outlined his analysis in *Verbal Behavior*, which describes a group of verbal operants, or functional units of language. The primary verbal operants, which are most often initially discussed in relation to teaching children with Autism, are mands, echoics, receptive, imitation, tacts, and intraverbals. A word has various functions and until a child is able to use the word across all functional domains, he/she has not fully learned the meaning of the word. This is accomplished in many ways, one of which is the use of specific teaching procedures.

Verbal operants, along with the motivative operants, come together in teaching language. Once the child has a strong echoic or imitative repertoire other functions of language are taught by prompting and differentially reinforcing. Operants are targeted and taught through errorless learning, mixing and varying targets, interspersing easy and hard tasks, and teaching to fluency. Teaching Verbal Behavior can be effective for students with language delays or language disorders, whether they will speak, sign, use visual communication, or other forms of augmentative communication, and whether they are early, intermediate, or advanced learners. Examples of some of the widely known developers of Verbal Behavior include Jack Michael, Mark Sundberg and James Partington.

Training standards: In addition to the training standards indicated in this document, the BSC must have specific training in Verbal Behavior to implement this type of treatment. At minimum, the BSC should have foundation knowledge in one of the comprehensive VB approaches. For TSS with no prior experience working with this model, the

requirements are a minimum of one full day of in-service training, as well as a minimum of six to 10 hours of one-to-one guided practice for the specific child with whom the TSS will be working.

Generative Instruction/Precision Teaching/Fluency

Generative instruction is based on the premise that complex behavioral repertoires develop when component repertoires are appropriately sequenced, instructed, and rehearsed. Fluency Based Instruction involves instructional delivery, instructional design, and precision teaching. Skills are practiced with a range of instructional procedures, including discrete trial instruction, direct instruction, errorless learning procedures, discrimination training, incidental teaching, and instructional timings. These skills are practiced and timed daily and performance is graphed on the Standard Celeration chart. The Standard Celeration Chart was developed by Lindsley and allows for instructional decision making. Children practice until they reach the aim. Fluency is performance that is easily executed (retention) whenever necessary for as long as needed (endurance), not easily distracted (stable), can be applied in new settings (application), and easily combined with other performances to figure out skills or knowledge (adduction). Examples of some of the widely known developers of Generative Instruction include Ogden Lindsley and Kent Johnson.

Training standards: In addition to the training standards indicated in this document, the BSC must have specific training in Generative Instruction to implement this type of treatment. At minimum, the BSC should have foundation knowledge in one of the comprehensive Generative Instruction approaches. For TSS with no prior experience working with this model, the requirements are a minimum of one full day of in-service training, as well as a minimum of six to 10 hours of one-to-one guided practice for the specific child with whom the TSS will be working.

Naturalistic/Incidental Teaching

Incidental teaching or incidental training are a set of formalized procedures used to reach a specific objective by capitalizing on natural, unplanned activities or through the planned introduction of learning opportunities in the person's typical environment. Programs addressing behavior reduction, communication training, etc. should be integrated with other programs, e.g., self-care skills training, by using incidental teaching techniques for the former during the sessions for the latter (BCBA Task List, 2nd edition, March 1997). Examples of some of the widely known developers of Naturalistic/Incidental Teaching include Gail McGee, Philip Strain, Sally Rogers.

Positive Behavior Support

The goal of positive behavior support is to support people with disabilities to be as independent as possible, enjoy life, live a normal life, and overcome problem behavior using an ABA basis. This model opposes aversive techniques and is often the basis of

special education programs. Examples of some of the widely known developers of Positive Behavior Support include Glenn Dunlap, Patricia Mirenda, and Robert and Lynn Koegel.

II. Additional Modalities

In this section, modalities which are not based on ABA principles are discussed. ***While many children may benefit from these interventions, they are not recommended as stand-alone behavioral health treatment programs.***

Training standards: It is recommended that each treatment team member receive a minimum of six hours of clinical training/guided practice, specifically geared towards implementing the technique (s) utilized, such as DIR, TEACCH, Social Stories, and Visual Strategies. This training should be provided by a senior clinician with a minimum of two years of relevant training and/or experience combined, and documented upon completion of this training. The training may be internal or external to the provider. Ongoing clinical supervision/consultation is recommended, and based upon individual needs of the clients and expertise of each staff member.

Appropriate recipient:

- Children of any age may be appropriate for these interventions.
- A diagnosis on the Autism spectrum.
- Families must be able to play an active role in treatment planning, implementation, and follow through of treatment recommendations.

“Rule outs”:

- Families that cannot commit to actively participate in treatment.
- Children with severe impairments who respond most successfully to intensive, structured, behavioral approaches.

Appropriate plan (items to include in the treatment plan):

- Detailed behavior plan (targeting specific behaviors to be addressed by the interventions).
- Information regarding transfer of skills to caregivers and other natural supports.
- A specific list of services to be provided and where.
- Documentation of integration with other services such as special education or other treatment.
- Set defined treatment goals and objective outcomes measures for the specific intervention (s).
- The plan should be compatible with the goals of the primary interventions.
- Plan for transitioning to another level of service or supports.

Frequency, Intensity, and Duration of Intervention:

- Recommendations for child will be based on child’s individual needs.

- Parents should be active participants in all aspects of treatment.
- The duration and intensity of treatment will vary widely. Considerations should include age, severity of Autism, family participation, rate of progress, other health considerations, additional levels of services, and community activities in which the child is involved.

A. Floortime/Greenspan/Developmental Individual-Difference Relationship-Based (DIR)

Also known as "Floortime," the DIR (Developmental Individual-Difference, Relationship-Based) Model targets emotional development, in contrast to other approaches, which tend to focus on cognitive development, following a developmental model, and has a child centered focus. This model targets personal interactions to facilitate mastery of developmental skills. The model teaches parents how to engage the child in happier, more relaxed ways, and hypothetically lays stronger framework for future neurological/cognitive development.

These interventions emphasize the child's:

- Affect and relationships.
- Developmental level.
- Individual differences (in motor, sensory, affective, cognitive, and language functioning).

Floortime does not focus on specific areas for competency. Research is limited in the support of treatment efficacy for children with Autism. This approach is based on hypotheses, not research, and is often viewed as a more child directed (passive - replace) approach to intervention.

B. TEACCH, Treatment and Education of Autistic and related Communication-handicapped Children.

TEACCH is a comprehensive intervention system that provides a variety of services to individuals with Autism and their families across all age periods. This program has operated since 1972 within the Department of Psychiatry of the University of North Carolina, Chapel Hill, with state funding. TEACCH focuses on adapting the environment using visual organizers and/or cues to assist the child with Autism in reaching independent functioning, developing visual processing skills, and overcoming behavioral challenges. In the TEACCH classroom, areas for special activities have clear boundaries. There are picture or picture-word schedules for individual children and for the class. Individual work systems are organized to maximize independent functioning and capitalize on the child's affinity for routines. Spontaneous functional communication is a language goal of TEACCH, and alternative modes of communication such as pictures, manual signs, and written words are used when speech is particularly difficult for the child. This approach is most often used in a classroom setting, but may be adapted to home or community settings as well.

C. Social Stories

Social Stories, also known as Social Scripts, is an approach that was developed by Carol Gray in 1991 to help students with Autism understand rules of a game. It has since been developed further to address the need to understand subtle social rules of typically developing children. This approach attempts to address the child's difficulty in taking the perspective of another person, known as "Theory of Mind" deficits. Social Stories are used to clarify social expectations for individuals with ASD, address issues from the child's perspective, redefine social misinterpretations, and provide a guide for conduct or self-management in specific social situations. These stories or scripts are specific to the person, addressing situations which are problematic for that individual. Social Stories typically are comprised of four types of sentences: perspective, descriptive, directive, and control. Each type of sentence is included in the story at a recommended frequency ratio. The Social Story can be read to or by the person with Autism, and as treatment progresses, the individual becomes more adept at writing his or her own stories with assistance from the treatment staff, as needed. The stories are re-read regularly, to help reinforce the individual's ability to interpret perspectives of others and to modify their own behavioral responses accordingly. The desired (and reported) outcomes of this approach include: stabilization of behavior specific to the situation being addressed, reduction in frustration and anxiety of students, and improved social behavioral functioning when this approach is consistently implemented.

Advantages include:

- Its ability to specifically address social deficits by teaching positive alternative social behaviors.
- Its ability to tailor to individual and specific needs.
- Flexibility in implementing this intervention across environments.

D. Visual Strategies

Linda Hodgdon, M.Ed., CCC-SLP is a speech pathologist who has pioneered the development of Visual Strategies for individuals with ASD. Communication deficits are often the underlying factors contributing to problems in social interaction, educational performance, and behavior. It is generally agreed that most children with ASD are **visual** learners, who understand what they **see** more effectively than what they **hear**. Many of these children demonstrate strength in understanding **visual** information compared to their ability to respond to what they hear. Using visual strategies to support communication provides an effective way for understanding both receptive and expressive communication. For many individuals with communication challenges, the use of visually supported communication is more effective and efficient than simple dialogue.

Visual tools assist students in processing language, organizing their thinking, remembering information and many other skills necessary to participate effectively. The visual tools used can range from body movements, environmental cues, pictures, objects, and written language, all of which can support the child's developing communication skills. Treatment professionals can also create visual tools to help meet

specific communication needs. These may include: visual schedules, choice boards, tools to give information, and tools to manage behavior. While social interaction requires multiple and rapid shifting of attention and focus, children with Autism may experience difficulty accomplishing these skills at the speed necessary to participate effectively in communication interactions. They can have difficulty rapidly interpreting information, particularly auditory information. Students may be accurately interpreting only fragments of communication messages. These processing deficits may result in disruptive behaviors, as the individual becomes confused or misinterprets a complex social interaction.

Visual tools are effective in creating an environment that is more predictable and understandable. They may include: schedules, calendars, step-by-step directions, choice boards, and written household or classroom rules. The use of visual strategies can be incorporated into most treatment approaches, and can be seen as an additional method of communicating and structuring the individual's daily experience. Visual Strategies can benefit many children, especially the child with Autism. Visuals can be pictures, words, actual items, or a combination that can be utilized to enhance learning, understanding, communication, increase independence, and functional skills, e.g., making choices, transitioning, understanding routines, schedules, changes, new situations, rules, and numerous other situations.

E. Picture Exchange Communication System (PECS)

The Picture Exchange Communication System (PECS) was developed as a unique augmentative/alternative training that teaches children and adults with Autism (and other communication deficits) to initiate communication. PECS begins with teaching a student to exchange a picture of a desired item with a "teacher" who immediately responds to the request. The training protocol is based on B.F. Skinner's book, *Verbal Behavior* which reported that when functional verbal operants are systematically taught using prompting and reinforcement strategies, the development of independent communication occurs. The system builds on previous learning and teaches discrimination of symbols and building sentences. PECS involves six specific stages with Stage I teaching the child to initiate communication by exchanging a single picture to Stage VI which teaches students to comment about things in their environment both spontaneously and in response to a question (adapted from Pyramid Educational Consultants website, 2006).

F. American Sign Language

Sign language is commonly associated with hearing impaired individuals; however, it has also been used to teach people with developmental disabilities who have little or no communication skills. Research has demonstrated that teaching sign language along with speech can potentially accelerate a person's ability to speak. Sign language can be useful for those individuals who have little or no verbal abilities or communication skills as well as individuals at various levels of functioning. Many of the negative behaviors sometimes demonstrated by children with Autism are often attributed to an inability to

communicate to others. Learning sign language in conjunction with speech may stimulate verbal language skills and potentially aid in the development of more appropriate coping behaviors (Adapted from Edelson, Stephen, (2005), *Signed Speech or Simultaneous Communication*).

Non-Behavioral Health Interventions/Modalities

The interventions and modalities discussed in this section include those that are not primarily provided through BHR services. It is strongly suggested that the BHRS providers maintain a peripheral role in the exploration of these adjunct interventions. Rather, parents of children with Autism should be referred to the professionals in each specialty who are most qualified to make treatment recommendations and to provide related services accordingly. It should be noted that this is not a comprehensive list.

Communication Modalities

Because many children with ASD have significant communication impairments, behavioral health providers need to be familiar with an array of communication approaches in order to maximize the effectiveness of their behavioral interventions. These include, but are not limited to: the Picture Exchange Communication System (PECS), discussed above, American Sign Language (ASL), discussed above, Language Boards, and Augmentative Communication Aids (i.e., Dynavox).

Speech and Language Therapy

Remediation of Speech and Language deficits in children including (but not limited to) receptive and expressive language impairments, auditory processing disorders, syntax deficits, articulation impairments, voice and fluency impairments, and pragmatic language deficits. Commonly, children with Autism are treated for expressive language delays, articulation, auditory processing (receptive and/or understanding/comprehending language) and pragmatic language deficits. Speech and Language Therapy can be a key component to any home/school program. A variety of approaches are utilized, including: Developmental-Social Pragmatics, Auditory Processing, and Treatments for Motor Speech Disorders.

Sensory Integration Therapies

Sensory integration is a neurobiological process which is innate. It refers to the process of integrating and interpreting environmental sensory stimuli. In sensory integrative dysfunction, as seen with many children with ASD, sensory input is not integrated or organized appropriately in the brain. This may result in varying developmental deficits which subsequently affect information processing and behavior. For these individuals, one or more senses may be involved, and can be either over- or under-reactive to stimulation, that is, the dysfunction can involve either hyper- or hypo-sensitivity to

stimuli. Such dysfunction may underlie a range of stereotypic, repetitive behaviors, including rocking, hand flapping, whirling, jumping, and spinning. Sensory integration techniques, such as pressure-touch, can facilitate attention and awareness, and reduce overall excessive sensory arousal. Such techniques are described by many individuals with ASD, including Dr. Temple Grandin, as providing relief from extreme sensory experiences.

Sensory integration deficits may be manifested by the child's over- or under-responsiveness to sensory input, unusually high or unusually low activity level, or fluctuations between these extremes. Gross and/or fine motor coordination problems are also common when these three systems are dysfunctional and may result in speech/language delays and in academic underachievement. Behavioral manifestations may include impulsivity, distractibility, and a general lack of planning. Children with ASD and sensory integration deficits also usually have great difficulty adjusting to new situations and tend to react with frustration, aggression, or withdrawal.

While sensory integration techniques are clearly beneficial for many children with ASD, it is strongly emphasized that these approaches generally are within the domain of the child's physical health providers, rather than behavioral health clinicians. Evaluation and treatment of basic sensory integrative processes must be performed by occupational therapists and/or physical therapists.

Although sensory integration programs are developed by professionals in the fields of physical and occupational therapy, there are many procedures which the child's caregivers can implement with adequate training from those practitioners. In general, however, it is recommended that these interventions be provided by the child's family and other primary caregivers. While less physically intrusive activities such as sand play and the use of varying textures (shaving crème, paint, clay) can be beneficial to children, and may be incorporated into the child's treatment plan, active participation of the parent or other primary caregiver is always needed. The necessity of primary caregiver involvement is even more critical when more intrusive or invasive physical activities, such as pressure, swinging, jumping on a trampoline, and brushing are being contemplated. As indicated previously, these interventions are not considered to be within the realm of behavioral health services, and should be included in the child's treatment only when provided by the primary caregiver, and/or the activity is recognized as only an adjunct to the child's regular behavioral health services.

Professional services which may involve sensory integration training include, but are not limited to: Occupational Therapy, Physical Therapy, Auditory Integrative Training, and Patterning.

Biomedical Treatments

Diets: Some individuals with Autism exhibit low tolerance for and/or allergies to a variety of different substances including yeast and gluten products. The most commonly applied diets are the Gluten-free/Casein-free (GF/CF) and Yeast-free

diets.

Vitamin/Nutritional: There is some clinical evidence which supports the use of some vitamins. Among the most commonly used are: Vitamin B6 and Magnesium, Folic Acid, Antioxidants (Vitamins A, C, E, Beta Carotene, Coenzyme Q10, Zinc), Dimethylglycine (DMG), Glutathione, and Metallothionein.

Psychopharmacology: Although there is no one medication used to treat Autism and related conditions some medications have been prescribed to alleviate specific symptoms, and behaviors such as aggression, seizures, hyperactivity, obsessive/compulsive behavior, anxiety, attention deficit related behaviors, and others.

Biomedical: Other interventions such as chelation therapy and secretin injections have also been used to treat the symptoms of ASD.

Note: BHRS and other behavioral health providers are STRONGLY DISCOURAGED from making any direct or specific recommendations to parents regarding the use of biomedical treatments, but to defer to professionals who specialize in the respective areas within this domain, such as nutrition, medicine, and psychiatry. Parents should be advised to consult directly with these professionals if considering any biomedical treatments. Most biomedical treatments require prior screening and monitoring for possible side effects by a qualified physician.

Other

This category includes an array of therapeutic services and approaches which have been utilized as part of a multi-disciplinary treatment model for children with ASD. As with other services not in the domain of BHRS, these interventions, when utilized, should be provided by specialists with the training and expertise necessary within their respective fields. Once more, while this list includes a number of subcategories, it is not intended to be exhaustive of all services which might be beneficial for children with ASD. These approaches may include: Equestrian Therapy, Music Therapy, Vision Therapy, Dolphin Therapy, Computer Therapy, Biofeedback, and other related therapies.

Coordination of Care

BHRS providers must ensure that care is coordinated and service linkage is provided with other involved systems including, but not limited to:

- Physical health, including contact with the primary care physician and ensuring documentation of a physical within the past 12 months.
- Education/vocational systems.
- Occupational and Speech Therapy.
- Child Protective Services.

- Juvenile Probation.
- Other behavioral health providers such as Intensive Case Management, psychiatric evaluation and medication monitoring, etc.

When indicated, the BHRS team should assist the family in obtaining developmental, psychiatric, or neuropsychological evaluations for children and adolescents with ASD, or when the diagnostic picture for an individual is unclear, or treatment progress has reached a plateau.

Special attention must be given to service delivery in school settings. The BHRS provider, particularly the BSC (and the TSS) assigned to the client, is expected to meet with school staff, in the family's presence, prior to the delivery of any services in the school setting. The purpose of the service delivery in the school setting must be clearly defined and must be directly related to the treatment of the child's identified behavioral health needs.

The use of BHRS in the school system is appropriate as a therapeutic behavioral health care service. However, there are specific guidelines for use of these services, as the school is a separate and independent system, with its own structure, rules, methodologies, and culture.

To allow for regular and adequate communication between the BHRS staff and school personnel, it is essential for interagency meetings to be scheduled periodically, beginning prior to the initiation of services in the schools. At these meetings, it is also necessary that input be gathered from all those working with the child, and including the classroom teacher, guidance counselor, principal, or other staff who interface with the child. It is emphasized that TSS service is not a stand-alone mental health service. Thus, introduction of this service to the school should be the domain of a mental health professional who works on the child's treatment team. This may be a Behavioral Specialist Consultant, Mobile Therapist, outpatient therapist, or TSS supervisor. The meetings are intended to clarify and address a number of critical issues, including:

- The child's immediate needs.
- Efforts the school has made to address the child's needs.
- School-related goals and objectives in the treatment plan.
- Specific hours and settings within the school where TSS service will be provided.
- Roles of the TSS worker.
- Designated mental health professional(s) providing TSS oversight.
- Mechanisms of communication among those serving the child.
- Specific data to be obtained to indicate treatment efficacy.
- Mutual expectations of the school and mental health staff and the family.
- Methods of addressing confidentiality issues.
- Criteria for service tapering and discontinuation.

It is strongly suggested that, prior to the initiation of BHRS in the school, the topic of the term of care, the level of intensity and the plan for transferring skills/interventions associated with the treatment plan is discussed openly with the school staff and

caregivers. This is necessary to insure that services are utilized to empower the child and his/her natural support system to function independently after BHRS has ended.

The role of each BHRS staff member in the school must be clearly delineated. The BSC is often the individual who introduces the BHRS model to the school staff. The BSC serves as a consultant with others on the team, the school staff, and the child and family. This person also facilitates the design of a behavioral modification plan. The BSC also designs the treatment program(s) and monitors the treatment interventions delivered by the MT and TSS worker. As needed, the BSC facilitates the revision of behavioral plans and treatment programs to meet the child's needs.

In contrast to the BSC, the MT works primarily in direct therapeutic interactions with the child and family. The MT uses a strengths-based model of intervention, and utilizes techniques specifically appropriate to the child's condition, abilities, and needs. For children with Autism, the MT is likely to focus on assisting the child and family in building the child's social and pragmatic communication skills, providing family therapy around issues specific to the child's diagnosis.

The TSS worker functions to carry out the interventions developed by the BSC and others on the treatment team. While the TSS worker supports and redirects the child, it is also the function of this staff person to transfer appropriate interventions to the child, other identified caregiver, family, and teacher by working collaboratively with them. The TSS worker also records data and documents the child's progress in treatment.

It is the responsibility of the provider to communicate with the school staff so that they have a clear understanding that the TSS worker can and should exchange information and collaborate with the classroom teacher if services are prescribed in the school. It is also essential for the provider to reinforce with the parents and school staff that services may be tapered and/or discontinued if clinically appropriate. This is a desirable outcome of effective intervention, as it reflects the success of the treatment in supporting the child's independent functioning.

Assuring cultural competency:

BHRS providers are expected to support the ongoing development of cultural competence within their programs. The BHRS team is expected to be committed to learning from the individuals serviced and to identifying strengths and recognizing the uniqueness of each child and family. Providers should engage in open, respectful communication with children, families and caregivers about culturally based values and belief systems that need to be considered when intervening with a child.

VI. Discharge Planning Process

The eventual goal of BHR services is to facilitate transfer of skills to the child and family which would ultimately lead to the development of the child's independence and discharge from these services. Discharge criteria are to be included in the development of the initial treatment plan, and revised accordingly thereafter. Target goals for

discharge from service are useful in helping to establish expectations regarding length of stay in the program.

Although services to children with ASD may span several reauthorization periods, BHRS providers are expected to help families understand the process of preparation for discharge. Providers should remind families that the services can be increased or decreased, according to need, but that the ultimate measure of successful intervention is the ability to transition the client to a less intensive, less restrictive level of care.

The working relationships between families and the BHRS staff are often very intimate and intense. Providers should discuss with families the emotions associated with the discharge process, recognizing that services are intense and are delivered in the families' homes.

There will be occasions when BHRS are not meeting the needs of the child/adolescent and/or family and services will be terminated by the provider or by the family. In such situations, the BHRS provider is expected to frame the decision positively for the family and assist the family in exploring other service options and/or other service providers.

A discharge summary is required and the member's case manager must be notified upon the closing of BHRS.

Providers are expected to link families with step-down resources and to assist, as needed, in the successful transition to those services. Providers are expected to facilitate the transition to other levels of care to ensure continuity of care and follow-up.

VII. Outcomes

All BHRS providers are expected to have an outcomes measurement program, consistent with their agency-wide continuous quality improvement plan. At a minimum, providers are expected to utilize progress updates in their treatment plans as well as gather member and family satisfaction data on at least an annual basis. Quality improvement initiatives in response to satisfaction survey results are expected. Providers are also expected to administer a standardized functional assessment, analyzed in aggregate to assess the impact of services.

Summary

In preparing and reviewing these guidelines, it is clear that a number of issues merit further exploration:

- Families, funders, and service providers could benefit from more detailed information regarding the intended as well as actual outcomes of services provided to children and adolescents with Autism and PDD.
- This report addresses utilization of services from the perspective of the HealthChoices program only. There are other resources (Early Intervention, Mental Retardation, Medical Assistance, Education, Pediatrics, Families and others) that

- play an equally significant role.
- There is an opportunity to look in more depth into the detail data that is and will become available to understand more fully issues such as:
 - The relationship between the specific skills and interventions and the successful treatment of the recipient.
 - The development of observable outcome measures.
 - The development of successful plans to transition children and families into other levels of service and support.
 - The role of support groups for both children and families in the successful long-term evaluation of the effectiveness of services.

VIII. Quality Improvement

Documentation Standards for Treatment Plans, Progress Notes, Discharge Summaries, and Additional Documentation:

Treatment Plan: The treatment plan identifies the child's strengths, including family and community strengths. It includes measurable objectives for treatment and conveys this to the child/family in a way in which they will understand. The treatment plan should identify realistic goals and set the pace by identifying the timeline for working on the treatment goals. Specific interventions to use with the child/family are identified with the consideration of the cultural perspective in treatment. The roles and responsibilities of each team member are identified in reference to the goals and objectives in the plan. Discharge criteria and a plan for a reduction of service are included as well as a crisis/safety plan.

Progress Notes: All progress notes are to include the date, start/end time of each treatment session, and the domain in which the service is occurring. It should also identify the participants of the session, the goals/measurable objective for which the session pertains, the interventions used, and the client's response to the intervention. Other information that is to be included in the progress notes include the method of coordinating services with other team members, any specific occurrence that influenced the session, the plan and date for the next session, and the staff member's signature with credentials. Documentation is to be commensurate with time spent in the treatment session.

Additional Documentation: The client's chart should include the following additional documentation:

- Information regarding internal treatment team or supervision meetings.
- Communication with the prescriber.
- Communication with other treatment team members.
- Correspondence with the family.
- Treatment consent.
- The child/family's bill of rights.
- Releases of information.
- Provider choice form.

- Parent education documents.
- Incident reports.
- Childline reports.
- Encounter forms.
- Parent's signature on all treatment plans.
- Parent signature on other BHRS documents (if indicated by the agency's policy and procedure manual).
- All required notification forms for BHRS reporting.
- Standardized scales.
- Coordination of services with the child's primary care physician (PCP).

Discharge Documentation: The following documentation must be completed for each child upon discharge from BHRS services:

- A discharge summary is prepared by the lead BHRS clinician and sent to the Community Care care manager within two weeks of discharge. The summary must include the disposition plan and discharge appointments. The provider should also obtain the appropriate releases such that the MCO, county, parent, new service provider, and others, as needed, receive the discharge summary.
- The BHRS provider is responsible for assuring that referrals for behavioral health services and to other service systems for continued care have been made, even though such referrals are often assigned to a case manager or the family at the final ISPT.
- As per access standards, if a follow up behavioral health service is recommended after discharge from BHR services, the first appointment must occur within seven days of discharge from BHR services.
- After the child is discharged from BHRS, Community Care will follow up with the family to assure that appointments have been attended. If not, Community Care will assist the child/family in making a follow up behavioral health appointment.

Addendum I

LIFE DOMAIN FORMAT FOR PSYCHIATRIC/PSYCHOLOGICAL EVALUATIONS: INITIAL AND CONTINUED CARE

2nd Edition

Note: This format is applicable to both initial and continued care evaluations. However, when writing an evaluation for continued care, it is recommended that Section III, Relevant Information, begin with an additional subheading called Brief Update that identifies and briefly summarizes the key events and changes during the most recent service period. The remainder of Relevant Information then follows the usual format, e.g., Strengths, Concerns, etc.

I. Identifying Information:

- Places the child in individual, family, cultural, residential, and educational/vocational contexts, e.g., age, date of birth, gender, race, ethnicity, cultural/religious beliefs, name and grade in school, type of class setting.
- Identifies family and household members, including each biological parent, stepparents, and siblings/half-siblings. Identifies marital status of parents and nature of child's contact with a non-custodial parent. Identifies employment status of current parental caregivers.
- Identifies custody of the child, and child's legal status, e.g., adjudicated or not. Identifies other team members, including involved professional agencies/systems, e.g., MH/MR, C&Y, juvenile justice, case management, child psychiatrist, special education, etc. and community supports.

II. Reason for Referral:

- A. Determine medical necessity for initial care or continued care service request.
- B. Identify additional purposes, as relevant, e.g., monitor medication or respond to crisis.

III. Relevant Information (begin with *Brief Update*, if a continued care request):

A. *Strengths*:

- Child/adolescent strengths, in multiple domains.
- Special attention to motivation and ability to form relationships and use support.
- Areas of greatest competence and independence.
- Family and community strengths.

B. *Concerns*:

- Clinical basis for current service request and recommended treatment.
- Nature, frequency, severity, and history of the child's behaviors/symptoms/serious emotional disturbance (SED) of concern.
- Identification of both externalized behaviors and internalized symptoms, comparing present to past.
- Other identified needs and concerns.

C. *Family:*

- Family composition (including relevant extended family), family relationships, strengths/concerns.
- For child in substitute care, foster family and natural family included.
- Family cultural and spiritual beliefs and practices, as relevant.
- Family history of psychiatric disorder, as relevant.

D. *School/Vocational:*

- The child's academic, social, and behavioral adaptations, including relationships with school peers and with teachers and/or level of functioning in vocational programming.
- Efforts to date of school to address current problems. Characteristics of current class setting.
- Current or past use of school-based services, if relevant.
- Current or past educational testing, CER, and IEF, Prior school placements.

E. *Community:*

- Place of residence-family home or apartment, group home, RTF, etc.
- Community activities and attachments.
- Use of leisure time.
- Community employment, current and in past.
- Degree of church or spiritual involvement.
- Nature of neighborhood, in terms of resources and culture, safety, specific conditions.
- Specific stressors, as relevant.

F. *Peer Relationships:*

- Patterns of peer relationships in the neighborhood and in school, including similarities and differences between the two settings.
- Predominant age of peers-same-aged, older, or younger-and gender of relationships.
- Predominant activities with peers, formal and informal. Nature of peer culture.

G. *Drug and Alcohol:*

- Child's current use/abuse of drugs and alcohol-type, frequency, severity.
- Child's past history of use.
- Child's past drug and alcohol treatment, response to treatment, involvement in self- help groups.
- Family substance abuse history, where relevant, including nature of use, type and effectiveness of treatment.

H. *Medical/Developmental:*

- Medical illness, acute or chronic infection, physical limitation, brain or other injury, past surgery.
- Lead or other toxicity.
- Medication allergies as relevant.

- Developmental history: pregnancy, delivery, neonatal period, developmental milestones.
- Mental retardation, atypical development, autism/PDD.
- Trauma history: neglect, physical abuse, or sexual abuse.
- Gender preference, when relevant and with consent of the child, and other issues of sexuality. Past pregnancy, when relevant.

I. *Legal:*

- Custody.
- Adjudication as delinquent or dependent.
- Other delinquent status indicators: probation, placement in juvenile facility, incarceration.
- Outstanding legal issues: pending charges, community service requirement, other.

J. *Services:*

- **Service History** - services used in past, reason, level of participation, and effectiveness. Include all levels of care, psychotropic medication, out-of-home placements (mental health and other), and services from other systems.
- **Service Update:**
 - Current services-including hours and sites-with summary of recent service history.
 - Impact of services:
 - Role of service providers and of family.
 - Progress/degree of attainment of treatment goals and objectives. Identify effective and ineffective interventions.
 - Receptivity of the child and family to services, and level of participation.
 - Nature of planned modifications of goals and services.
 - Specific indications for, and use of, psychotropic medication. Include names and dosages and, where applicable, blood levels. Indicate medication adherence and effectiveness of medication, when in use.
 - Nature of regular clinical updates to prescriber by involved mental health staff, during most recent service period.

K. *Other:*

- Other domains as relevant, or added to earlier information.

IV. Interview:

- A. Identification of participants.
- B. The child/adolescent's appearance, hygiene, self-care.
- C. The child/adolescent's manner of relating to the interviewer and other identified adults present. Emphasis on level of engagement, cooperation, openness to input.
- D. The child/adolescent's formal mental status. Include verbalized goals, needs, requests, response and commitment to treatment, degree of understanding and insight, other individualized ideas of the child/adolescent, and ability to contract for safety, when relevant. Compare with previous contacts, if applicable.
- E. Key issues/themes addressed, and areas of agreement/consensus.

V. Discussion:

- A. Overview/summary.
- B. Hypothesis/formulation.
- C. Diagnostic considerations.
- D. Rationale for recommended services.
- E. Nature of consensus and agreements with the child/adolescent, family if present, and others.
- F. Prognosis.

X. Diagnosis: 5-Axis diagnosis.

XI. Recommendations:

- A. Identification of each specific behavioral health service recommended, listing the amount, duration, and scope of each.
- B. Other treatment recommendations, both global and specific (e.g., other needed services and interventions for the team to consider; psychotropic medication referral or recommendation; additional recommended assessment(s); community referral(s) and natural supports; education and/or vocational recommendations; consultation with primary care physician; other)
- C. For continued care requests, criteria for service tapering or modification of level of care, and recommendations to increase natural supports.

Addendum II

Recommended Assessment Tools for Evaluators

This is a list of frequently used assessment tools among professionals working with children with ASD. As new measurements are being developed regularly, this list represents some, but not all such assessment techniques. It is not intended to represent an exhaustive list, but reflects many of the assessment tools currently being utilized.

- Screening tools:
 - Autism Symptoms Checklist (screening tool)
 - Modified Checklist for Autism in Toddlers (M-CHAT)
- Diagnostic tools:
 - Autism Diagnostic Observation Schedule (ADOS)
 - Childhood Autism Rating Scale (CARS)
 - Gilliam Autism Rating Scale (GARS)
- Treatment outcome measures:
 - Behavior Rating Instrument for Autistic & Other Atypical Children (BRIAAC)
 - Autism Treatment Evaluation Checklist (ATEC)
 - Assessment of Basic Language and Learning Skills (ABLLS)

Addendum III

Glossary of Acronyms and Terms

AAC: Assistive Augmentative Communication: A speech-language therapists' term for communication using a picture board or recorded messages activated by buttons, etc.

ABA: Applied Behavior Analysis, a style of teaching which uses a series of trials to shape a desired behavior or response. Skills are broken down into their simplest components and then taught to the child through a system of reinforcement.

ABC: Autism Behavior Checklist: A diagnostic device for Autism; a checklist containing a list of behaviors and weighted scores which appear to be capable of measuring the level of autistic behaviors in individuals.

ADA: Americans with Disabilities Act, US law that ensures rights of persons with disabilities with regard to employment and other issues.

Adaptive PE: Adaptive Physical Education

ADI: Autism Diagnostic Interview, a diagnostic scale for Autism developed by the Medical Research Council in London, England. It is a standardized, semi-structured parent interview that can be used to assess children and adults with a mental age of 18 months and up.

ADOS: Autism Diagnostic Observation Schedule, a standardized, semi-structured play session that allows the examiner to observe communicative and social behaviors that are associated with Autism.

AIT: Auditory Integration Training,

Aphasia: The complete or partial loss of ability to use or understand language.

Apraxia: A disorder of voluntary movement, consisting of partial or total incapacity to execute purposeful movements, without impairment of muscular power, sensibility and coordination. The person has difficulty sequencing movements in the service of a goal. May be specific to speech.

Apraxic: Having to do with apraxia or a person with apraxia.

ARI: Autism Research Institute

AS: Asperger's Syndrome, a developmental disorder on the Autism spectrum defined by impairments in communication and social development and by repetitive interests and behaviors. Unlike typical Autism, individuals with Asperger's Syndrome have no significant delay in language and cognitive development.

ASA: Autism Society of America

ASD: Autistic Spectrum Disorders

ASL: American Sign Language, a system of gestures, hand signals and finger spelling used in North America and other English-speaking locales.

Atypical Autism: A general term for conditions that are close to but do not quite fit the set of conditions for Autism or other specific conditions.

Auditory Integration Training (AIT): A technique used to relieve hearing dysfunctions by "retraining" the ear to hear in a more balanced fashion.

Augmentative Communication: The use of aids to help a child with Autism communicate his/her wants and needs. For example, photographs and picture exchange communication.

Autistic savant: An individual with autism who displays incredible aptitude for one or two skills, e.g., amazing musical or artistic ability.

Autistic Spectrum Disorders: Term that encompasses Autism and similar disorders. More specifically, the following five disorders listed in the DSM-IV: *Autistic Disorder*, *Asperger's Disorder*, *PDD-NOS*, *Childhood Disintegrative Disorder*, and *Rett's Disorder*.

Bayley Scales: A developmental assessment used for children age one month to 3 ½ years old. It is comprised of a mental, motor, and behavior scale. This scale has a mean of 100 and a standard deviation of 15.

BHRS: Behavioral Health Rehabilitation Services: Community based mental health treatment available to children with mental health needs in Pennsylvania.

BSC: Behavior Specialist Consultant. Refers to an advanced degree behavioral specialist providing services through BHRS.

CAN: Cure Autism Now

CARS: Childhood Autism Rating Scale, a test developed at TEACCH to diagnose Autism. The child is rated in 15 areas on a scale up to 4 yielding a total of up to 60. Ranges are then considered to be non-autistic, autistic or severely autistic.

CBCL: Achenbach Childhood Behavior Checklist, a diagnostic instrument.

CDC: Center for Disease Control, a US Government agency.

CF or C/F: Casein free, referring to a diet which restricts the intake of casein

CHAT: Checklist for Autism in Toddlers

DAN: Defeat Autism Now

DAS: Developmental Apraxia of Speech

DD: Developmental Disabilities

DH: "Developmentally Handicapped" DSM-III, DSM-IV and & DSM-IV-TR: The official system for classification of psychological and psychiatric disorders prepared by and published by the American Psychiatric Association.

DTT: Discrete Trial Training, a short, instructional training which has three distinct parts: a direction, behavior, or consequence. Many discrete trial programs rely heavily on directions or commands as the signal to begin the discrete trial.

DVD: Developmental Verbal Dyspraxia

Dyspraxia: A problem with planning, initiating, sequencing, and carrying out voluntary

movements.

EAHCA: The Education for All Handicapped Children Act. See "Public Law 94-142."

Early Intervention (EI): A state-funded program that is designed to identify and treat developmental problems or other disabilities as early as possible.

Echolalia: Repeating words or phrases heard previously. The echoing may occur immediately after hearing the word or phrase, or much later. Delayed echolalia can occur days or weeks after hearing the word or phrase. Functional echolalia is using a quoted phrase in a way that has shared meaning and to serve a purpose.

Electroencephalogram (EEG): A test that uses electrodes placed on the scalp to record electrical brain activity. It is often used to diagnose seizure disorders or to look for abnormal brain wave patterns, or to assist in differential diagnoses.

Facilitated Communication: The use of a keyboard by a person with Autism. The training begins with simple questions that have predictable answers, and becomes increasingly complex with less physical support from the facilitator.

FAPE: Free and Appropriate Education

FC or F/C: Facilitated Communication

FCT: Facilitated Communication Training

FEAT: Families for Early Autism Treatment

GARS: Gilliam Autism Rating Scale

GF or G/F: Gluten free, a dietary approach to restrict the intake of foods with gluten.

HFA: High-functioning Autistic or High-functioning Autism, individuals with Autism who are not cognitively impaired.

HIPAA: The Health Insurance Portability and Accountability Act, the federal law which insures comprehensive protection for the privacy of personal health information.

Hyperlexia: Ability to read at an early age, but often without linking the words to what the words mean.

Hypotonia: Low muscle tone.

ICD-10: *International Classification of Diseases of the World Health Organization* (ICD-10 currently): A numerical system used (sometimes in conjunction with DSM criteria) to classify diseases and disorders, including Autism.

IDEA: Individuals with Disabilities Act, a US Law mandating the "Free and Public Education" a.k.a. FAPE of all persons with disabilities between the ages of 3 and 21.

IEP: Individualized Educational Plan, a plan that identifies the student's specific learning expectations and outlines how the school will address these expectations through appropriate special education programs and services. It also identifies the methods by which the student's progress will be reviewed. For students 14 years or older, it must also contain a plan for the transition to postsecondary education, or the workplace, or to

help the student live as independently as possible in the community.

ISPT: Interagency Service Planning Team Meeting, a regularly scheduled meeting which occurs throughout BHRS, to obtain input from all members of the treatment team.

LCSW: Licensed Clinical Social Worker

LD: Learning Disability

Leiter International Performance Scale: A nonverbal assessment of intelligence, used primarily with children with communication difficulties. It gives both an IQ score, and an age equivalent for the child's level of functioning.

LFA: Low-functioning Autistic or Low-functioning Autism, referring to an individual with Autism who also has cognitive limitations.

LKS: Landau-Kleffner Syndrome: Also known as acquired aphasia with convulsive disorder, is characterized by a progressive loss of the ability to understand language and use speech, following a period of normal speech development. It is accompanied by seizure activity and is typically diagnosed through a sleep EEG.

LRE: Least Restrictive Environment

Macrocephaly: The term used to describe the condition of having a head circumference two standard deviations above average, which translates to a clinical definition of greater than the 97th percentile.

Mainstreaming: Placing an exceptional child with typical peers in a regular classroom.

Magnetic Resonance Imaging (MRI): A diagnostic technique that uses the magnetic qualities of body chemicals to produce an image of the brain.

Microcephaly: The term used to describe the condition of having a head circumference two standard deviations below average, producing an abnormally small head, and a congenitally small brain.

MR: Mentally Retarded or Mental Retardation

MSDD: Multi-System Developmental Disorder, Stanley Greenspan's term for an Autistic-like set of symptoms.

MT: Mobile Therapy or Mobile Therapist, refers to therapy services available through BHRS

NAS: National Autistic Society

Neuroleptic: A drug producing analgesia, sedation, and tranquilization or a similar condition.

Neurologist: A doctor specializing in medical problems associated with the nervous system, specifically the brain and spinal cord.

Neurotypical: A term used for neurologically normal individuals.

NICHCY: National Information Center for Children and Youth with Disabilities

NIH: National Institutes of Health, a US government agency.

NIMH: National Institutes for Mental Health, a US government agency

NT: Neurologically Typical, Neuro-typical, or Neurotypical, this term is used in to refer to people who do not have Autism.

NOS: "Not Otherwise Specified" (see "PDD-NOS")

OT: Occupational Therapist: Individuals who specialize in the analysis of purposeful activity and tasks to minimize the impact of disability on independence in daily living. The therapist then helps the family to better cope with the disorder, by adapting to the environment and teaching sub-skills of the missing developmental components. Occupational therapists often provide Sensory Integration Therapy.

Occupational Therapy: A therapy provided by an occupational therapist that assists in the individual's development of the fine motor skills that aid daily living. It can also focus on sensory issues, coordination of movement, balance, as well as self-help skills such as dressing, eating with a fork and spoon, and grooming. It can also address issues pertaining to visual perception and hand-eye coordination.

PDD: Pervasive Development Disorder

PDD-NOS or PDD/NOS: Pervasive Development Disorder--Not Otherwise Specified

PECS: "Picture Exchange Communication System"

Perseveration: Repetitive movement or speech, or sticking to one idea or task; has a compulsive quality to it.

PHP: Partial Hospital Program, a daily treatment program providing services more intensive than outpatient treatment, but less restrictive than a residential setting

Pica: Ingestion of nonfood items (crayons, paint chips, etc).

Proprioceptive: Capable of receiving stimuli originating in muscles, tendons, and other internal tissues.

PT: Physical Therapy

Public Law 94-142: Also known as The Education for All Handicapped Children Act of 1975 (EAHCA). US federal law providing funds to states that maintain certain standards in their education of handicapped children, e.g., providing a free and appropriate education in a least restrictive environment.

RTF: Residential Treatment Facilities; includes facilities that are accredited by the Joint Commission on the Accreditation of HealthCare Facilities (JCAHO) and those that are licensed and supervised by the Department of Public Welfare but are not JCAHO-accredited.

Self-Stimulatory: A term for behaviors whose primary purpose appears to be to stimulate one's own senses, e.g., rocking one's body. Many people with Autism report that some 'self stims' may serve a regulatory function for them, e.g., calming, adding concentration, or shutting out an overwhelming sound. Other examples include hand-flapping, toe-walking, spinning, and echolalia.

Sensorimotor: Pertaining to brain activity other than automatic functions

(respiration, circulation, sleep) or cognition. Sensorimotor activity includes voluntary movement and senses like sight, touch, and hearing.

SI: Sensory Integration, this is a term applied to the way the brain processes sensory stimulation or sensation from the body and then translates that information into specific, planned, coordinated motor activity.

SIB: Self-Injurious Behavior

SIT: Sensory Integration Therapy

SLP or S-LP Speech and Language Pathologist: Individuals who specialize in the area of human communication. They focus on communication, rather than speech, as a way to increase the child's ability to impact and to understand their environment.

SSI-DC: Supplemental Security Income-Disabled Child, a government program.

STAP: Summer Therapeutic Activities Program: An intensive summer treatment program for children with exceptionalities, often delivered in a camp-like setting.

TEACCH: Treatment and Education of Autistic and Related Communication Handicapped Children, this is a therapeutic approach broadly based on the idea that individuals with Autism more effectively use and understand visual cues. It focuses on promoting independence by using items such as picture schedules to break down tasks step-by-step.

TSS: Therapeutic Staff Support services or worker, refers to direct services available through BHRS

Theory of Mind: The ability to understand that others have beliefs, desires, and intentions that are different from one's own.

Vineland Adaptive Behavior Scales: An assessment measure sometimes used to evaluate a child's functioning in social, communication, behavioral, and self-help areas.

Wechsler Intelligence Scale for Children (WISC-IV): An individually administered clinical instrument for assessing the intellectual functioning of children.

Wechsler Preschool and Primary Scale of Intelligence-Revised (WPPSI-3): A clinical instrument similar to the WISC-IV, except for children ages 3-0 to 7-0.

Addendum IV

REVIEW OF PSYCHOSOCIAL TREATMENT LITERATURE IN AUTISM

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March 8, 2005

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The following paper provides an overview of the psychosocial treatment literature in Autism. There have been hundreds of papers written on Autism and the various treatment approaches to this disorder over the past four decades. It is certainly beyond the scope of this paper to attempt to review this entire literature. Instead, the purpose of this paper is to provide guidance in identifying Empirically Supported Treatments (ESTs) and those treatments that may hold some promise in addressing the many needs of children with Autism. This has been accomplished through examination of a number of reviews of the Autism literature (some of whose results are summarized below) as well as reading many of the papers that describe treatment outcomes.

Pervasive Developmental Disorders, which include Autistic Disorder, Asperger's Disorder and Pervasive Developmental Disorder – Not Otherwise Specified, affect between 40 and 60 children per 10,000 (Fombonne, 2003). For purposes of this paper, the term Autism will be used to refer to these three Pervasive Developmental Disorders. While the core features of Autism include deficits in social interaction and communication as well as repetitive and restrictive patterns of behavior, children with Autism also often present with serious behavior problems such as tantrums, aggression, self-injury, disruptive behavior, hyperactivity, and noncompliance. Because these secondary behavior problems may interfere with habilitative and educational efforts, they are often addressed by both mental health and educational interventions. Interventions commonly used for children with Autism include specialized educational programming, pharmacotherapy, and a range of psychosocial treatments (National Research Council, 2001). It is the last intervention category, psychosocial treatments that will be the focus of this review.

Within the Autism field, there are numerous treatments that have been popularized through books, television news stories, and on the Internet. However, the popularity of a particular treatment is not necessarily a demonstration of its effectiveness. Treatment modalities such as auditory training and facilitated communication, for example, have had many adherents but have not been shown to be efficacious. The true test of an intervention is the ability to demonstrate its effectiveness in a controlled study.

As a way to organize this review, we have chosen to place each treatment for Autism into one of four categories, based upon the level of research support for its efficacy. The categories include: 1) **Strong Support** (based upon either ≥ 2 randomized trials or ≥ 6

controlled single subject trials; II) **Moderate Support** (≤ 1 randomized trials or ≤ 6 controlled single subject trials); III) **Limited or No Support** (no randomized and only case reports); and IV) **Ineffective Treatment** (either not recommended or controlled studies have consistently shown that the treatment does not work). Table 1 lists the interventions that are reviewed in this paper and the category in which each has been placed.

Table 1. Psychosocial Interventions by Category

Type I Interventions	General ABA Interventions	Other ABA Interventions	Other ABA Interventions
	<ul style="list-style-type: none"> • Reinforcement • Time out • Extinction • Antecedent-based procedures • Instruction-based procedures 	<ul style="list-style-type: none"> • Discrete Trial Training • Pivotal Response Training • Incidental Teaching • Functional Communication Training 	<ul style="list-style-type: none"> • Visual Supports • Peer-Mediated Interventions • TEACCH • Video Modeling • Scripts • Verbal Behavior
Type II Interventions	ABA & Non ABA Interventions		
	<ul style="list-style-type: none"> • PECS • Positive Behavior Supports • Social Stories • Fluency Training • Parent Training 		
Type III Interventions	Non ABA Interventions		
	<ul style="list-style-type: none"> • Floortime • Sensory Integration • Social Skills Curricula • RDI 		
Type IV Interventions	ABA & Non ABA Interventions		
	<ul style="list-style-type: none"> • Secretin • Facilitated Communication • Auditory Training 		

I. APPLIED BEHAVIOR ANALYSIS

Applied behavior analysis (ABA) interventions have been successfully used to treat children and adults with Autism and/or developmental disabilities since the 1960s. In addition to being the most frequently used interventions to address behavior problems, ABA techniques are commonly used to develop and maintain appropriate communication, social, and self-help skills. ABA interventions are also commonly included in treatment packages that address the needs of children with Autism. There have been hundreds of single-subject design studies published during the past 40 years documenting the efficacy of ABA interventions to treat a range of behavior problems in children and adults with developmental disabilities (see reviews by Didden et al., 1997; Horner et al., 2002; Lennox et al., 1988; Scotti et al., 1991; 1998).

Interventions have historically included the use of techniques such as differential reinforcement, extinction, time out, token economies, and response cost. However, during the past 15 years there has been a gradual shift in the types of ABA interventions used in treatment. This shift is characterized by a move away from primary dependence on consequence-based treatments to a greater emphasis on antecedent-based and instruction-based interventions. In addition, the use of functional assessments has characterized most of the recent research on behavior problem management. A number of other well-known interventions also fall under the ABA umbrella, including the Picture Exchange Communication System (PECS), Discrete Trial Training, Positive Behavior Supports, Functional Communication Training, Pivotal Response Training, TEACCH, and Incidental Teaching. A review of the literature documenting the effectiveness of these interventions appears below.

a. Behavior Problem Management

ABA (behavior modification) interventions have been designated as Empirically Supported Treatments (ESTs) for addressing the behavioral concerns of individuals with Autism by the American Psychological Association Division 12 Task Force on Promotion and Dissemination of Psychological Procedures (Chambless & Ollendick, 2001). Such behaviors include aggression, self-injury, disruptive behavior, stereotypy, inappropriate social behavior, pica, rumination, noncompliance, food refusal, insomnia and inappropriate vocalizations. A number of reviews of the behavioral literature in Autism and developmental disabilities have been conducted that lend support to this decision by the Division 12 Task Force. For example, Lennox et al. (1988) reviewed 162 studies from 1981-1985 involving treatments to decrease behaviors in individuals with mental retardation (including individuals with Autism). Level I treatments included procedures such as environmental changes, antecedent control, reinforcement, instructions (verbal prompts), and self-management while Level II treatments included extinction, social disapproval, overcorrection, contingent observation (a form of time out), response cost, and visual screening. Table 2 displays the mean percent effectiveness of Level I and II treatments for various behavioral concerns:

Table 2. Treatment Effectiveness from Lennox et al., 1988

	Mean % Effectiveness	
	Level I	Level II
Self Injury	70%	55%
Aggression	63%	68%
Disruption/Destruction	68%	33%
Stereotype	85%	80%
Inappropriate Social	82%	5%

As demonstrated on Table 2, Level I procedures are often as effective, if not more effective, than the more restrictive Level II procedures. More recently, Horner et al., (2002) reviewed the Autism behavioral treatment literature from 1996-2000 and

identified nine experimentally controlled studies involving children 8 years of age and under. Aggression and tantrums were the most common target behaviors, followed by stereotypy and self-injury. Management and instruction-based interventions, e.g., prompts, functional communication, and visual strategies, were most commonly used, followed by extinction, reinforcement of appropriate behavior, and punishment. The mean reduction in problem behavior across the nine studies was 85% (a rate slightly greater than was documented by Lennox et al., 1988).

In their recent examination of five reviews of the ABA literature, Horner et al. (2002) drew the following conclusions:

- ABA treatments work equally well for individuals with developmental disabilities, e.g., mental retardation, and those with Autism. In other words, ABA interventions do not need to be modified to be effective for children and adults with Autism.
- Similarly, factors such as age, IQ, and type or level of disability are unrelated to intervention effectiveness.
- The inclusion of a functional assessment prior to implementing treatment appears to increase the likelihood that an intervention will be successful
- ABA interventions can be successfully implemented by parents and teachers (although more difficult problems may require the services of more highly trained specialists).
- No intervention has been identified as consistently better than most.
- While most interventions are superior to Differential Reinforcement of Other Behavior (DRO), the inclusion of DRO improves the effectiveness of other treatments.
- Relatively few studies have examined generalization and maintenance, resulting in little understanding of the factors that can impact long-term effects.
- Relatively few studies have compared ABA treatments with each other.

Based upon our current knowledge of ABA interventions, the following are considered Best Practices for developing a behavior support plan for a child with Autism (Horner et al., 2002):

- Problem behaviors should be prevented by creating an environment with “a) a high level of child engagement, b) access to preferred activities and rewards, c) consistent and predictable system of scheduling, d) continual access to typical peers, and e) an immediate and effective system of communication” (Horner et al., 2002, p. 435). In addition, the environment should limit opportunities for maladaptive behaviors to be reinforced.
- The target behavior should be operationally defined.
- An assessment should be conducted that identifies specific antecedents that predict the occurrence of the target behavior and possible consequences that serve to reinforce or maintain the behavior.
- A functional behavior assessment or functional analysis should be conducted to identify the possible functions of the target behavior (s).
- A behavior support plan should be developed with the following:
 - Make antecedent changes, e.g., change classroom seating, change how tasks

are presented, that will serve to prevent the target behavior from occurring. This may also involve addressing possible setting events, e.g., poor sleep, health problems, and home problems, that affect the rate and occurrence of the behavior.

- Teach socially appropriate behaviors and communication skills that will replace or serve the same function as the target behavior.
- Prevent inadvertent reinforcement of the target behavior and promote the reinforcement of appropriate alternative behaviors.
- Develop specific consequences, e.g., extinction or redirection that immediately follow the occurrence of the target behavior (s).
- Establish an ongoing data collection system.

b. Home Based Behavioral Programs

The following section summarizes the research data for a number of home-based behavioral programs.

Discrete Trial Training: Discrete Trial Training is an ABA teaching technique that was popularized by Dr. Ivar Lovaas, following the publication of a 1987 paper describing its success in treating a group of young children with Autism (Lovaas, 1987). The Lovaas study involved the provision of 40 hours per week of intensive in-home discrete trial training for a period of 24 months. Since that time, other studies have suggested that similar results may be obtained with a 20-25 hour per week program. Discrete trial training is curriculum-driven, typically teaching the child with Autism a range of skills, starting with basic motor imitation and continuing to include skills such as picture, color and letter identification, conversational speech, and motor skills. Critics of discrete trial training have cited problems with generalization, the lack of appropriate peer models, as well as a possible over-dependence upon instructor prompts to initiate activities and use language. There have been a growing number of studies examining the effectiveness of this intervention. A representative sample of this research is summarized below. As can be seen, there has been only one truly randomly assigned study and others using control groups that were not randomly assigned (although matched to the treatment groups in terms of IQ, age, etc.). A couple of the studies were conducted in school settings, but are included here in order to keep all the discrete trial literature together.

Table 3. Selected Discrete Trial Studies

Study	Subject Ages & IQ	Type of Treatment (Tx) and Children per Group	Tx Length	Results
Lovaas, 1987	<= 46 months 17/19 MR in Intensive Tx Group 39/40 MR in the other two Tx Groups	3 groups (group assignment based on therapist availability) • => 40 hrs/wk of DT (19) • <= 10 hrs/wk of DT (19) • Community Tx (21)	=> 2 yrs => 2 yrs => 2 yrs	At follow in first grade: • 40 hr/wk group had mean 30 pt IQ increase with 47% with normal IQ • No change in IQ in other groups. Only 2% had normal IQ.
Smith et al., 1997	<46 months	2 groups (group		Follow-up when children

	IQ < 35	assignment based on therapist availability) <ul style="list-style-type: none"> • => 30 hrs/wk (11) • <= 10 hrs/wk (10) (Data based upon archival records)	=> 2 yrs Up to 2 yrs	were 5-10 yrs of age. Intensive Tx group had higher IQ (36 vs 24) and more expressive speech. Both groups had fewer behavioral problems.
McEachin et al., 1993	9-19 years Both MR and nonMR	A 7-9 year follow-up of subjects in the Lovaas 1987 study who received 40 hrs/wk of DT (19) vs. subjects who received 10 hrs/wk of DT (19).	NA. This is a follow-up 7-9 yrs post tx	<ul style="list-style-type: none"> • 47% of 40 hr/wk group in regular ed; 58% had an IQ > 80 • 0% of 10 hr/wk group in regular ed; 17% had an IQ > 80
Smith, Buch & Gamby, 2000	35-45 mos. IQ 45-65	Followed 6 children receiving parent directed DT (mean 26 hr/wk). Used multiple baseline to demonstrate tx effects.	2-3 yrs	5/6 rapidly acquired skills following initial tx. 2/6 improved on standardized tests.
Smith, Groen & Wynn, 2000	18-42 months	2 groups (randomly assigned) <ul style="list-style-type: none"> • 25 hrs/wk of DT* (15) • Parent Training (13) 	3 yrs 3-9 mos.	At follow-up, the DT group outperformed the parent raining group on measures of intelligence, visual-spatial skills, language, and academics, but not adaptive functioning or behavior problems
Elkesith et al, 2002	4-7 yrs IQ>50	Schoolbased Treatment (group assignment based on therapist availability) <ul style="list-style-type: none"> • DT (13) • Eclectic (12) Mean 28 hrs/week treatment for both groups	1 year	<u>IQ Gain:</u> DT: 17 pt. Eclec: 4 pt <u>Language Gain:</u> DT: 25 pt Eclec: 1 pt <u>Adaptive Beh. Gain:</u> DT: 11 pt Eclec: 0 pt
Sheinkopf & Siegel, 1998	2-4 yrs 19 Autistic 2 PDD NOS	2 groups (not randomly assigned) <ul style="list-style-type: none"> • Parent DT + School (11) (# of hours varied and are not provided) • School only (11) 	(mean) 20 mos. 18 mos.	<ul style="list-style-type: none"> • DT group had a mean 25 point higher IQ at end of tx; all had IQ>65; had slight decrease in symptoms • School group had 6/11 with IQ >65; had slight increase in symptoms
Bibby et al, 2001		Followed 66 children treated by parents using DT	Mean 30.6 mos.	<ul style="list-style-type: none"> • No change in IQ • 8 point increase in adaptive behavior • 5 point increase in mental age Parent run DT may not be as good as professionally run DT

The cumulative results of the above research on Discrete Trial Training indicate that it should be considered as a Type I intervention for children with Autism. There remains

some controversy regarding the appropriate number of hours of therapy. Groups of professionals who have been asked to review this data and make recommendations have generally suggested that a minimum of 20-25 hours per week be provided and that services begin as early as possible, e.g., NYS Department of Health Early Intervention Program, 2003.

Murdoch Program (Birnbrauer & Leach, 1993): The Murdoch Early Intervention Program in Western Australia also involved the use of an intensive, home-based treatment program. Similar to Discrete Trial Training, the program used one-on-one instruction and utilized ABA instructional interventions. A group of nine children with PDD (mean age of 39 months) received an average of 18.75 hours per week of treatment over a two year period. A control group of five children who did not receive behavioral treatment were also identified and followed. Progress was assessed by “blind” raters who were unaware of group membership. At the end of two years, four of nine children in the ABA treatment group had assessed IQ scores ranging from 89-103. Two years earlier the independent evaluators had determined that the children were “untestable.” While additional gains were noted in language, social behavior, play, and adaptive behavior, scores remained below age-level. Of the remaining children in the treatment group, four made moderate gains and one made minimal gains. Conversely, only one child in the control group made impressive gains in adaptive functioning and language, but not on IQ scores. A second child made moderate gains while the remaining three children’s gains were minimal. Measures of parental stress also found a considerable decrease for parents in the treatment group but minimal change for those in the control group.

May Institute Program (Anderson et al., 1987): The May Institute studied 14 children with Autism (mean age of 43 months) who received 15-25 hours per week of intensive in-home behavioral treatment for one to two years. Assessments conducted after one year of treatment found mental age and social-age scores to increase somewhat (2-23 months) for 13 of 14 children. Of 11 children whose language skills were also assessed, nine experienced gains of 3-18 months. Similar gains were noted for those children who continued in treatment for a second year. Overall, eight children gained skills at rates above that of normal development. However, none of the children were fully integrated into regular education settings at the end of the study (unlike the findings reported by Lovaas, 1987). The results were not as robust as that reported by Lovaas (1987), but utilized considerably fewer hours of treatment and for fewer years. Additionally, the children were on average a year older and had lower IQs.

University of California (Sheinkopf & Siegel, 1998): A group of researchers at UC-San Francisco followed a group of 11 children with Autism/PDD (mean age just under three years) who received intensive in-home behavioral treatment (for an average of slightly less than 20 hours per week). A second group of 11 children with Autism/PDD who did not receive intensive children were matched to the treatment group. Both groups attended school as well. At an 18-20 month follow-up, most of the children in the behavioral treatment group had substantial gains in IQ while the control group evidenced moderate gains or less (mean of 89.7 for the treatment group versus 64.3 for

the control group). While there was no significant difference between groups at follow-up on the number of autistic symptoms, symptom severity was significantly less for the treatment group in comparison to controls (although all children continued to meet diagnostic criteria for Autism/PDD).

c. School-Based Behavioral Programs

Dawson and Osterling (1997) reviewed the literature on early intervention programs for children with Autism and identified six "Common elements of effective intervention." The New York State Department of Health Early Intervention Program (1999) summarized these elements as follows:

- **Curriculum content.** The curricula of the programs emphasize five basic skill domains, including the following abilities: 1) to attend to elements of the environment that are essential for learning, especially to social stimuli; 2) to imitate others; 3) to comprehend and use language; 4) to play appropriately with toys; and 5) to interact socially with others.
- **Highly supportive teaching environments and generalization strategies.** The programs first try to establish core skills in highly structured environments and then work to generalize these skills to more complex, natural environments.
- **Predictability and routine.** Since the behavior of children with Autism is easily disrupted by changes in environment and routine, the programs adopt strategies to assist the child with transitions from one activity to another.
- **Functional approach to problem behaviors.** Since young children with Autism often show problem behaviors, the programs first try to prevent the development of these behaviors by structuring the environment. If problem behaviors persist, the programs use a functional approach that involves the following steps: 1) recording the behavior; 2) developing a hypothesis about the function that behavior serves for the child; 3) changing the environment to support appropriate behavior which allows the child to cope effectively with the situation; and 4) teaching appropriate behaviors to replace problem behaviors.
- **Plans for transition from preschool classroom.** The programs teach "survival" skills that children will need later on in order to function independently in preschool or school classrooms.
- **Family involvement.** The programs include parents as a critical component in the intervention for young children with Autism. Family involvement is an important factor or success of a program because parents can provide unique insight into creating an intervention plan and can provide additional hours of intervention. Including parents in the intervention can also help children achieve greater maintenance and generalization of skills and can help reduce parents' stress levels.

The national programs that were felt to meet these criteria included:

- Douglass Developmental Disabilities Center (behavioral model)
- Health Sciences Center, University of Colorado (developmental model)
- Learning Experiences - An Alternative Program for Preschoolers and Parents (LEAP) (Behavioral model)
- May Institute (Behavioral model)

- Princeton Child Development Institute (Behavioral model)
- Treatment and Education of Autistic and Communication-Handicapped Children (TEACCH) (Behavioral model)
- Walden Preschool (Behavioral Model)
- University of California at Los Angeles (UCLA) Young Autism Program (Behavioral model)

Each of these programs has published research on outcomes. According to Dawson and Osterling (1997), outcome data is available for 150 children across the eight programs. All eight programs appeared to be successful in fostering significant developmental gains. Average IQ gains across programs were 20 points (with most children starting out in the programs functioning with IQs less than 70). Four of the programs reported that approximately 50% of children were enrolled in integrated classrooms upon entry into the public school (although differing philosophies across school districts in regard to inclusion makes it difficult to determine the meaningfulness of this statistic). However, there are few studies comparing program outcomes versus a control group and no studies comparing any of these models.

d. Overview of Early Intervention Behavioral Treatments

A number of other studies have been published documenting the efficacy of specific interventions to enhance communication and social development. The vast majority of work in this area continues to involve ABA interventions. A review of evidence based practices for young children with Autism was recently published (Odom, et al., 2003) and summarizes the well-controlled, single subject design research published between 1990 and 2002. A total of 37 studies were identified that employed experimental designs and demonstrated effectiveness through multiple replications of treatment effects. Odom et al., (2003) divided this research into 11 intervention categories and three levels of effectiveness: a) **Well Established** (more than nine studies in support of the intervention); b) **Emerging and Effective** (at least six studies supporting the intervention); and c) **Probably Efficacious** (any intervention with less than six studies demonstrating efficacy).

Well Established Interventions: These included: a) *Adult-Directed teaching Strategies* such as verbal modeling to teach children to ask questions (Williams, Donley, & Keller, 2000) or using scripts to teach children to engage in conversation (Krantz & McClanahan) and b) *Differential Reinforcement Strategies*, such as differentially reinforcing language to obtain desired objects (Drasgow, Halle, & Ostrosky, 1998) or differentially reinforcing play as an appropriate alternative to stereotypy (Nuzzolo-Gomez et al., 2002). These well-established strategies are also integral to other behaviorally based programs such as Discrete Trial Training and most Naturalistic Teaching Interventions, e.g., Incidental Teaching, Pivotal Response Training, and Verbal Behavior.

Emerging and Effective Interventions: These included: a) *Peer-Mediated Interventions* such as teaching typical peers to support social interactions of students

with Autism (McGee et al., 1992), b) *Visual Supports* such as the use of visual activity schedules to promote independence in the classroom (Morrison et al., 2002), c) *Self-Monitoring* such as teaching children with Autism to monitor their own social interactions with peers (Shearer, et al., 1996), and d) *Family Involvement* such as using siblings to increase play in a children with Autism. These strategies are well established in the behavioral literature. For example, Peer-mediated interventions are frequently used in preschool programs that include children with Autism and typical peers, e.g., the LEAP Program, or Douglas Preschool Program, and have a strong support in the literature dating back to the 1970s. Visual supports were initially introduced in the 1970s by Eric Schopler and the TEACCH Project in North Carolina. The use of such supports has more recently expanded to include PECS (The Picture Exchange Communication System) and Visual Activity Schedules (Krantz, McDuff, & McCallahan, 1993). Parent and family involvement also has a long tradition in the Autism field with a number of programs serving preschoolers with Autism documenting the efficacy of their work with families, e.g., Harris et al., 2000.

Probably Efficacious: These included: a) *Video Modeling* (or video priming) such as the use of video to teach functional living skills (Shipley-Benamou et al., 2002), b) *Moderating Characteristics of the Task* such as providing activity choices as a way to improve performance (Carter, 2001), and c) *Positive Behavior Supports*, which includes the use of functional assessment, prevention strategies, differential reinforcement, and the teaching of alternative behaviors to address behavioral concerns (Dunlap & Fox, 1999). Video modeling has been used more frequently among older children with Autism, but also can be effective with younger children. Moderating task characteristics, including providing greater choice options, is often used as an antecedent prevention strategy. Finally, positive behavior supports is being used in hundreds of schools and serves as the basis for behavior support plans that are part of many children's IEPs.

e. Specific Early Intervention and School-Age Behavioral Treatments

Incidental Teaching: Incidental teaching has been an ABA approach for almost 40 years. Where discrete trial training involves prompting the child to make a response and then reinforcing correct responding, incidental teaching utilizes a somewhat more naturalistic situation to teach. According to Fenske, Krantz, and McClannahan (2001), there are four steps to incidental teaching: (1) arrange the child's setting so that it contains highly stimulating and interesting materials; (2) wait for the child to initiate an interaction, e.g., requesting an item; (3) request more elaboration of language (or approximations of speech); and (4) provide the item that was requested. In the area of language development, discrete trial training often is used to teach answering questions, e.g., "what's this?" or labeling. Conversely, incidental teaching usually focuses on spontaneous requesting, e.g., "I want milk." Incidental teaching and discrete trial training can be used in conjunction to teach language skills (Sundberg & Partington, 1999).

Incidental teaching is the primary mode of intervention in a number of model preschool programs for children with Autism, including the LEAP program in Pittsburgh, PA, the TEACCH program, and the Walden School in Atlanta, Georgia. It has been shown to

be effective in teaching skills such as reciprocal interactions (Odam & Strain, 1986) and language development (McGee, Krantz, & McClannahan, 1985). Incidental teaching has also made use of typically developing peers to assist in the teaching of social skills and language to children with Autism (McGee, Almeida, Sulzer-Azaroff, & Feldman, 1992).

Pivotal Response Training (PRT): This is an ABA, naturalistic approach that concentrates on teaching pivotal behaviors that can produce widespread changes in many other behaviors. Derived from work by Koegel, Schreibman, Dunlap, and Horner, e.g., Koegel, O'Dell, & Kiegel, 1987, the main components of PRT are: choice, clear instructions, reinforcement or approximations/attempts, use of natural reinforcers, e.g., requesting a ball results in obtaining a ball, and use of multiple cues, e.g., if teaching red, use a red shirt, a red car, and a red sock. PRT has been successfully used to teach complex social behaviors (Pierce & Schreibman, 1995), play (Pierce & Schreibman, 1995), as well as language skills (Koegel, O'Dell, & Kiegel, 1987) in young children with Autism. It has many similarities to Incidental Teaching.

Picture Exchange Communication System (PECS): The Picture Exchange Communication System (PECS) was first introduced by Bondy and Frost (1993). It was adopted as the statewide treatment modality for all Autism support classrooms in Delaware. PECS involves teaching primarily non-verbal children with Autism to use pictorial icons to make requests and to eventually engage in a short conversation at the highest level of proficiency. The actual training of a child to learn to initiate the use of a picture icon is conducted via an incidental teaching model. For example, a teacher knows that popcorn is a favorite food for a student. A piece of popcorn is held by the teacher and when the child reaches for it, the child is guided to place a picture icon for food (or popcorn) into the teacher's open hand. Following a number of training trials, the child progresses from: 1) spontaneously using a picture icon to request food, to 2) learning to discriminate among a range of icons, to 3) using simple sentences, e.g., "I want popcorn".

PECS has become extremely popular as an intervention for children with Autism. At least three case studies have been published reporting positive results with the use of PECS among fairly large groups of children (ranging from 21-85 subjects). Since 2002, there have also been at least four single-subject studies either demonstrating the efficacy of PECS or comparing PECS to another communication modality, e.g., sign language. Two of these controlled studies demonstrated both that PECS could be easily acquired and that there was also an increase in the spontaneous use of expressive language (Charlop-Christy et al., 2002; Ganz & Simpson, 2004). In the two remaining controlled studies PECS was compared to sign language (one involving adults with Autism and severe mental retardation). Results found that some individuals increased the use of spontaneous requests more rapidly with PECS while others progressed more rapidly with sign language (Chambers & Rehfeldt, 2003; Tincani, 2004). As there have been no randomized trials using PECS and four controlled, single-subject studies published, PECS is considered to be a Type II intervention. Below is a summary of selected PECS research studies.

Table 4: Picture Exchange Communication System (PECS) **Visual Strategies:**

Citation	Age	Diagnoses	Treatment	Design	Results
Charlop-Christy, et al. 2002	3-12 yrs (n=3)	Autism	Standard PECS training	Single subject; multiple baseline	All 3 children showed concomitant increases in verbal speech. Ancillary gains were associated with increases in social-communicative behaviors and decreases in problem behaviors.
Kravits et al, 2002	6 yrs (n=1)	Autism	Standard PECS training	Multiple baseline across settings	Increases in spontaneous language (use of the icons and verbalizations across settings PECS was implemented. Intelligible verbalizations increased in 2 of 3 settings; changes in peer social interaction noted in 1 of 2 school settings.
Matt Tincani 2004	5-6 yrs (n=2)	Autism	Compared PECS with sign language	Alternating Treatment Design	Sign > than PECS for rate of mands in one S, PECS> Sign for other S. Sign had > vocalizations during training for both S's.
Chamber & Rehfeldt, 2003	Adults (n=4)	Mental Retardation	Compared PECS with sign language	Alternating Treatment Design	3 of 4 S's met criteria using PECS faster than with sign. 3 generalized at another setting with PECS; 2 generalized with sign as well.
Ganz & Simpson, 2004	Preschool children (check this) (n=3)	Autism and developmental delay	Standard PECS training	Changing criterion design	PECS was mastered rapidly by all S's; word utterances increased in number of words and complexity of grammar.

Visual strategies subsume a number of behavioral interventions that utilize picture schedules as prompts to teach independence. These strategies attempt to capitalize on the relative strengths in visual processing that are seen in many children with Autism. Picture/visual schedules also provide a greater level of predictability in a child's environment. In addition, picture/visual schedules limit a child's dependence on verbal prompts and can provide a longer period of time for the child to process information. There have been a number of controlled studies documenting the ability of picture/visual schedules to increase independent work, independent play, and schedule following in classrooms serving children with Autism (Bryan & Gast, 2000; Hall, McClannahan, & Krantz, 1995; McClannahan, & Krantz, 1999; MacDuff, Krantz, & McClannahan, 1993). Such interventions can also be implemented at home by families of children with Autism (Krantz, MacDuff, & McClannahan, 1993). Based upon the fact that there are six or more single-subject design studies demonstrating the efficacy of visual strategies for children with Autism, this approach is considered a Type I Intervention.

Treatment and Education of Autistic and Communication Handicapped Children (TEACCH): TEACCH is a method that was adopted by the state of North Carolina in the 1970's. It was originally developed by Dr. Gary Schopler at the University of North Carolina at Chapel Hill, based upon the understanding that individuals with Autism process visual information more easily than verbal information. TEACCH has been adopted by service providers throughout the world. It is best known for structuring the classroom environment by providing visual cues (pictorial icons) that indicate that a particular activity is next, e.g., morning circle, or in what order to complete tasks. The TEACCH model falls within the behavioral tradition. However, unlike the discrete trial approach, it focuses more on generalization, functionality, incidental teaching, alternative communication techniques, and psycholinguistic approaches (Mesibov, 1997). TEACCH methods are used across the age spectrum, from toddlers to adults. Despite its popularity, there have only been a small number of controlled trials examining the effectiveness of the TEACCH model. One fairly recent study demonstrated that a group of children with Autism placed in a classroom utilizing the TEACCH model fared significantly better on measures of development, e.g., gross motor, cognitive, and adaptive behavior than matched group of children with Autism who were sequestered in an inclusion classroom with a support teacher (Panerai, Ferrante, & Zingale, 2002). Short (1984) compared the behavior of children on a waiting list with those receiving intensive TEACCH service. Those in the TEACCH group evidenced significant increases in appropriate play, social, work, and communication skills in comparison to the wait-list controls. Similarly, Ozonoff and Cathcart (1998) followed a group of children whose parents received an average of ten, in-home TEACCH training sessions (in which parents were instructed in the TEACCH model) and a group of "matched controls." Reassessments conducted at four months found that the treatment group had made significantly greater gains (versus controls) on measures of imitation, fine motor, gross motor, and nonverbal conceptual.

In their review of early intervention programs for children with Autism, Dawson and Osterling (1997) identified the TEACCH model as an "effective program." Additionally, the New York State Department of Health Early Intervention Program (1999) cited the

TEACCH model as a proven early intervention program for children with Autism. Based upon this and the results of randomized treatment trials demonstrating the effectiveness of TEACCH, the TEACCH model clearly meets criteria as a Type I intervention.

Functional Communication Training (FCT): FCT has been shown to be an effective treatment for addressing behavioral concerns in children with Autism. First introduced by Carr and Durand (1985), FCT involves identifying the function of a target behavior and then specifically teaching an alternative, more efficient behavior that serves the same function. For example, Braithwaite and Richdale (2000) successfully combined extinction with FCT (teaching an alternative way to request preferred objects) to treat a seven year old boy with Autism and severe aggression and self-injury behavior (SIB). Similarly, Ross (2002) combined extinction and FCT (the teaching and reinforcement of appropriate conversational responses) to decrease echolalia and inappropriate language in three children with Autism. Durand and Carr (1992) compared FCT versus time-out with 12 children with Autism who displayed challenging behaviors that appeared to be maintained by adult attention. While both interventions were initially successful, long-term results were better for the FCT group when the children were placed with teachers who were unaware of the prior intervention. FCT is considered to be a Type I Intervention for individuals with Autism.

Verbal Behavior: Verbal Behavior is an ABA intervention that focuses on teaching verbal behavior through a collection of highly effective teaching procedures taken from the science of behavior analysis. Many of the specific interventions are based on Skinner's 1957 book, *Verbal Behavior*, which detailed a functional analysis of verbal behavior. A number of books are now available that describe the steps to using Verbal Behavior interventions among children with Autism, e.g., Sundberg & Parington, 1998. There are also a growing number of single-subject, controlled studies that demonstrate the efficacy of this intervention for individuals with Autism, e.g., Sundberg et al., 2000, 2002; Parington et al., 1994, suggesting that procedures based upon Verbal Behavior approaches should be considered Type I Interventions.

Fluency Training: Fluency training is derived from the precision teaching model, which has a rich literature involving the enhancing of skills among children with learning problems and a range of other developmental disabilities (see Journal of Precision Teaching and Celeration). It supplements existing curricula by providing rules for decision making and emphasizes fluency. Because children with Autism often have difficulty generalizing acquired skills, increasing fluency has been proposed as a means of addressing this problem. While a number of papers have been recently published that suggest that fluency training may have an important role to play in programming for children with Autism, e.g., Kerr, Smyth, & McDowell, 2003; Kubina, Morrison, & Lee, 2002, we were unable to locate any controlled studies in the literature that demonstrate the efficacy of fluency training in this population. Based upon the large literature documenting the benefits of fluency training in other populations, we have designated this as a Type II Intervention, pending the publication of specific studies in Autism.

Scripts: The use of scripts has been shown to be an effective method of teaching children with Autism to engage in brief social interactions as well as short

conversations, e.g., Sarokoff, Taylor, & Poulson, 2001; Stevenson, Krantz, & McClannahan, 2000. While there has been concern that children might have difficulty deviating from such scripts or have difficulty in novel situations, some papers have shown that children taught scripts are able to generalize and expand their conversational skills. There have been enough published controlled studies of the use of scripts among individuals with Autism to consider Scripts to be a Type I intervention.

Video Modeling: Video modeling has shown some promise in a few papers as a means of teaching language and social skills to children with Autism. For example, Taylor, Levin and Jasper (1999) increased play-related statements in children with Autism using video modeling. Similarly, Charlop-Christy & Daneshvar (2003) used this intervention to teach perspective taking in a group of children with Autism. As there have been over six controlled, single-subject studies of video modeling among individuals with Autism, it is considered a Type I intervention.

Parent Training: A small number of randomized controlled trials of parent management training for children with Autism have been conducted, e.g., Drew et al., 2002; Jocelyn, Casiro, Beattie, Bow, & Kneisz, 1998; Diggle, McConachie, & Randle, 2002; Ozonoff & Cathcart, 1998; Smith, Groen, & Wynn, 2000; Sofronoff, Leslie, & Brown, 2004, clearly establishing the use of parent-mediated interventions for children with Autism. Additionally, many comprehensive early intervention programs for children with Autism include a major parenting training component, e.g., Dunlap, 1999; Harris et al., 2000; Koegel et al., 1999; Rogers et al., 2000. Typically, such programs include instruction in many of the Type I behavioral interventions, including reinforcement, time out, extinction, etc. However, there are no standardized parent training manuals, guidelines or programs that have been validated for use. Instead, parent training can differ considerably across studies. As a result, it is difficult to determine where to properly place parent training as a treatment intervention. We have identified parent training as a Type II Intervention because there has not been a series of studies on one particular intervention model.

II. NONBEHAVIORAL APPROACHES

Other Social Skills Training Approaches

Social Stories: Social stories are an intervention that were developed and popularized by Carol Gray, a special educator who had worked with children with Autism. A Social Story is a short story that describes a situation, concept, or social skill written in a format that is meaningful for people with Autism. There are four basic sentence types: descriptive, perspective, affirmative, and directive. Stories can be written to assist an individual learn certain skills, e.g., how to introduce yourself, or handle difficult situations, e.g., being teased by others. Social Stories are reviewed once a day or just prior to the situation they describe.

A review of the published research available regarding Social Stories intervention for children with Autism yielded 13 studies relating to effectiveness. All of the studies

reviewed used single subject research designs to test effectiveness of Social Stories. Out of the 13 studies, 10 were peer reviewed, used designs to reduce interfering variables and reported on the effectiveness of Social Stories in autistic children. A variety of experimental designs were used to evaluate effectiveness of Social Stories. AB case design, ABA, ABAB, withdrawal of treatments, multiple baselines across setting and subjects, combination designs, and ABAB with multiple baselines across subjects. Limitations found to be consistent across all studies and previous reviews included: 1) small number of subjects, 2) no control groups, 3) only two studies demonstrating brief maintenance of treatment effects, 4) no generalization data, and 5) no pure replication of Social Stories studies, i.e., in most cases, Social Stories was paired with other intervention, such as pictures, photos, reinforcement schedules, etc.

Overall, the empirical foundation regarding the effectiveness of social stories has improved in the past few years. The current available studies continue to have many limitations. Due to lack of experimental control, weak treatment effects or confounding treatment variables, it is difficult to determine if Social Stories alone were responsible for durable changes in important social behaviors (see review by Sansoti, Powell-Smith, & Kincaid, 2004). Thus, it is premature, based on the current literature, to suggest that social stories are an evidenced based approach when working with individuals with Autism. As a result, Social Stories remains a Type II intervention. Table 5 provides a summary of the research in Social Stories in Autism.

Table 5. Social Stories

Citation	Age	Diagnoses	Treatment	Design	Results
Scattone et al, 2002	7-15	N=3 Autism	Two subjects read the social stories aloud, prior to class or specific activity; for 3 rd subject social story was read to him by the teacher 1 hour prior to recess	Multiple baseline across subjects	Decreased disruptive behavior (chair tipping), staring, and disruptive shouting behavior <u>Limitations:</u> Confounding interventions. One subject was also receiving academic intervention to increase on-task behavior. Also teacher prompts may have provided more opportunities to practice the skills in the Social Story.
Lorimer et al, 2002	5	N=1 Autism	Two Social Stories reviewed the alternatives to tantrums and ways to gain positive attention. Stories were read twice per day.	ABAB	Effective in reducing tantrum behavior

Brownell, 2002	6-9	N=4	Musical Social Story	ABAC/ACAB counterbalanced design compared traditional printed social stories and musical equivalent	Both stories were effective in reducing TV and movie related echolalia and loud vocalizations in all 4 subjects
Theimann & Goldstein, 2001	6-12	N=5 Autism	Combined approach of Social Stories and feedback; two 30-minute sessions per week; Treatment sessions were broken down into three 10-minute segments	Multiple baseline across behaviors	Effective in improving social communication for all 5 subjects. Also assessed for generalization and social validity.
Hagiwara & Myles, 1999	7-10	N=3 Autism	Computer based Social Stories were read once a day.	Multiple baseline across behaviors	Minimally effective in improving hand washing completion for two subjects and increasing on-task behavior for the other subject. <u>Limitations:</u> Only 16 data points
Kuttler et al., 1998	12	N=1 Fragile X	Social Story was read prior to lunch and work time during the school day	ABAB	Effective in reducing temper tantrums
Ivey et al., 2004	5-7	N=3 Autism	Social Stories regarding novel events were read to the subjects by parents 1x per day for 5 days prior to the event change.	ABAB reversal	All three subjects increased participation level in novel activities following introduction to Social Stories
Adams et al., 2004	7	N=1 Asperger's	Parent reviewed social story prior to start of homework	ABAB	Social Stories intervention found to be a beneficial tool for reducing frustration behaviors exhibited during homework time
Barry & Burlew, 2004	7 & 8	N=2	Photograph of the subjects on daily basis during treatment phase. Following the stories, teacher created opportunities for subject to make	ABCD with multiple baseline across behaviors	Both subjects demonstrated the ability to make independent choices during free time play. No generalization or follow up.

			choices.		
Kuoch & Mirenda, 2003	3-6	N=3	Individualized Social Stories were developed for each subject. Following a baseline observation, Social Story was read to the subject prior to the situation where target behaviors typically occurred.	2 subjects ABA 1 subject ACABA	Social stories reduced the rate of target behaviors for all three subjects; good short terms maintenance when social stories were discontinued.

Developmental, Individual Difference, Relationship Model (DIR)(Greenspan, Wieder, & Simons, 1997): DIR (often referred to as Floortime) is a model that is based on both child development and psychoanalytic theories. Developed and popularized by Dr. Sidney Greenspan, it typically involves a significant number of hours a week (much like discrete trial training). Floortime involves having the parent or therapist conduct one-on-one sessions with the child for up to 20 minutes at a time. Relationship based interactions are emphasized in which the therapist often follows the child’s lead or interests to foster the development of communicative, social, and play skills (Gerlach, 2000). Despite its popularity, there remains no empirical evidence in support of this treatment. The only paper reportedly published that offers any data on children who have received Floortime Therapy was a retrospective chart review of 200 children conducted by Dr. Greenspan in 1997 (Greenspan & Wieder, 1997). While the report indicates that a significant portion of children responded to this therapy, no controlled studies of Floortime Therapy have been conducted. Hence, it remains classified as a Type III intervention.

The New York State Department of Health Early Intervention Program Clinical Practice Guidelines (2003) concluded that some aspects of the DIR model may be consistent with desired elements commonly used in other intervention approaches such as:

- Importance of child specific assessment.
- Individualizing the intervention to the child’s strengths and needs.
- Involving the family in the intervention.

However, the NYS Guidelines recommended that if interventions based on the DIR model are being considered for a young child with Autism, it is essential that the interventions:

- Set defined treatment goals and objective outcome measures.
- Define treatment goals appropriate for the individual child.
- Provide a baseline and ongoing assessment of the child’s progress.
- Provide for appropriate modification of the treatment plan based on the child’s progress, including consideration of other interventions if the child is not improving.
- Be coordinated with any other interventions that the child may be receiving to avoid any potential conflicts in establishing and achieving goals for intervention.

Finally, the NYS Guidelines concluded that:

- There is no adequate research evidence that interventions based on the DIR model are effective for treating Autism in young children.
- Interventions based on the DIR model may interfere with an intensive behavioral/educational program unless steps are taken to coordinate the two interventions.
- Although interventions based on the DIR model are not likely to be physically harmful, they are time intensive and may take time away from interventions that have shown to be effective.

Social Skills Curricula: A number of social skills curricula have been published that provide specific lessons and activities to teach a range of social skills, especially to high functioning children with Autism. Examples of such curricula include *Navigating the Social World* (McAfee, 2002) and *Do-Watch-Listen-Say: Social and communication interventions for children with Autism* (Quill, 2000). McAfee's book covers six lessons on recognizing and coping with one's emotions and 12 sessions on communication and social skills. Skills such as anger management and progressive relaxation are also taught as part of the curriculum. The use of conversational scripts and even some Social Stories are used as teaching tools. While certain aspects of the training package have been researched by others, e.g., anger management, problem solving, and relaxation, this has often involved other pediatric populations. Based upon our search of the literature, there appears to have been little research validating most of social skills curricula developed for children with Autism. However, such curricula provide much needed structure and guidance for those who are providing individual treatment to children with Autism. While this is clearly a highly promising area, we have chosen to consider social skills curricula as Type III Interventions until further research is conducted.

Relationship Development Intervention (RDI) (Gutstein, 2002): RDI was developed by Dr. Steven Gutstein and purports to teach "relationship intelligence." This includes emotional referencing, social coordination, declarative language, flexible thinking, relational information processing, foresight, and hindsight. Similar to many of the social skills curricula, Gutstein has provided manuals with specific activities to be covered at each session. The intervention can be implemented by a clinician on an outpatient basis or by parents at home. While Dr. Gutstein reports that many individuals have made significant gains as a result of RDI, there have been no peer reviewed published papers of which we are aware. While it appears to be a promising treatment, it remains a Type III Intervention until further research is conducted.

Other Treatment Approaches

Sensory Integration Therapy (SI): Sensory integration is a treatment procedure developed in the 1950 by Dr. Jean Ayers, to address problems and cognition in

children. This treatment over the years has been used for a variety of populations with neurodevelopmental disabilities. More recently this treatment has been recommended for children with Pervasive Developmental Disorder/Autism and Asperger's Disorder. Sensory integration is the ability to take information through the senses and integrate and organize this information in the brain. A child can have a dysfunctional sensory system in which one or more senses overreact or under-react to stimulation in the environment. Therapy for integration dysfunction is usually delivered by an occupational therapist or physical therapist who provides sensory or motor activities, usually in the form of play, to help the child better absorb and process sensory information. It focuses on three basic senses, tactile (touch), vestibular (sense of movement), and proprioceptive (body position/orientation in space). The goal of sensory integration therapy is to help the individual organize or modulate the sensory information that the brain receives, in order to have a more organized response to sensory stimuli.

Among children with Autism, commonly utilized sensory integration therapies include weighted vests, joint compression, deep pressure, hug machines, and brushing. There are no randomized controlled studies of sensory integration (Hender, 2001). Most of the published literature is comprised of clinical case studies, AB designs, or group pre and post measures. However, there are a couple of studies that may be of interest. Edelson et al., (1999) conducted a prospective study of 12 children with Autism comparing a hug machine versus a hug machine without pressure (control condition). The children had two 20 minute sessions per week for a six week period. Results found decreased tension and anxiety for the treatment group, especially for children who had the highest levels of anxiety. However, there were no significant differences between controls and treated children on behavioral measures at the end of the study.

Two additional controlled studies have used massage with children with Autism. While not specifically a sensory integration treatment, massage and touch was initially examined as a treatment for infants. Field et al. (1997) conducted a prospective, controlled study of 22 preschoolers with Autism, comparing the effects of massage versus quiet reading time. Treatment sessions were conducted for 15 minutes/day, two days/week for a four week period. While both groups improved, the massage group made significantly greater improvement on social behavior and decreased stereotypies than the control group. Escalona et al. (2001) replicated the Field et al. (1997) study with a group of 20 preschoolers with Autism who were randomly assigned to either a nightly bedtime massage by their parents or reading time for a one month period. Results suggested that the children in the massage group displayed less stereotypic behavior and exhibited more on-task behavior and social relatedness at school while experiencing fewer sleep problems at home.

Despite a few interesting studies of the effects of touch pressure and massage, reviews of the sensory integration literature as a whole offer minimal support for its use among children with Autism. Hoehn and Baumesiter (1994), who conducted a review of 105 sensory integration studies, concluded that, "The current fund of research findings may well be sufficient to declare sensory integration therapy not merely an unproven, but a demonstrably ineffective remedial treatment for learning disabilities and other disorders." Similarly, Vargas and Camilli (1999) conducted a meta-analysis of 76

articles and five masters' theses on sensory integration and concluded that individuals receiving sensory integration improved no more than those who did not receive therapy or received an alternative therapy. Finally, the New York State Department of Health Early Intervention Program (1999) concluded that sensory integration was deemed to have too limited empirical support to be specifically recommended as the primary intervention for children with Autism.

Facilitated Communication (FC): Rosemary Crossley first introduced facilitated communication (FC) in Australia in the 1970s as a technique to help individuals with cerebral palsy and physical disabilities communicate. Douglas Biklen began to use FC in the United States with people who had Autism in the late 1980s. Facilitated Communication derives from the hypothesis that children and adults with Autism or other developmental disabilities have a motor deficit that prevents them from expressing themselves even though they possess a sophisticated understanding of spoken and written language.

A number of reviews of the FC literature have been conducted and found similar results (Mosert, 2001; Jacobson, Mulick, & Swartz, 1995; Myles, 1996). All concluded that there is no empirical evidence to demonstrate that FC is an effective intervention for improving communication skills in individuals with Autism. In fact, well controlled studies have consistently refuted the viability of FC. In a 1998 policy statement by the American Academy of Pediatrics on Auditory Integration Training (Committee on Children with Disabilities, 1998), it was determined that currently available information did not support the claims of proponents that this treatment was efficacious. In addition, the New York State Department of Health Early Intervention Program (1999) review chose to recommend against the use of FC, due to lack of proven efficacy. Below is a summary of some of the FC studies.

Table 6: Facilitated Communication

Citation	Age	Diagnoses	Treatment	Design	Results
Regal et al., 1994	23-50	N=19 10 male 9 female	Questionnaire Facilitator and subject had individual sessions; 5x7 stimulus cards used to teach color, shape	Open trial Pre/Post measures	FC ineffective
Bebko et al., 1996	6-21	N=20 Autism 5 girls 15 boys	Individual sessions 96 trials per subject 3x4 index cards with pre-assigned pictures	Open trial; No control group Pre/Post	Ineffective in improving communication skills Inconsistent results on 7 month follow up Supports previous literature on FC as an ineffective treatment

Auditory Integration Training (AIT): Since its introduction in the United States in the early 1990s, AIT has generated enthusiasm as well as criticism. AIT has been promoted as a noninvasive treatment for auditory processing that is believed to lead to improved attention and decreased behavior problems. It has been extremely popular in the Autism community. Although parents cite numerous anecdotal and clinicians' clinical reports of treatment success, benefits have not been adequately demonstrated and generalized for any population.

In a recent review of the AIT literature, Sinah et al., (2004) identified six randomized controlled trials of AIT and one crossover study. A total of 171 subjects participated in these studies, ranging in age from three to 39 years. Four of the studies had fewer than 20 subjects and concealment was inadequate for all studies. Three studies (Bettison, 1996; Zollweg et al., 1997; Mudford et al., 2000) failed to demonstrate any benefit of AIT over control conditions. The remaining studies (Veale, 1993 [paper presentation at a Speech and Hearing Conference - not published], Rimland & Edelson, 1994, Edelson et al., 1999) reported improvements at three months for the AIT group based on improvements of total mean scores for the Aberrant Behavior Checklist (ABC). However, these findings are of questionable validity, as the ABC total mean score is an inappropriate use of this tool. Rimland (1995) also reported improvements at three months in the AIT group for ABC subgroup. However, Goldstein (2003) criticized the Edelson et al., (1999) study for having no matched control group, no randomization of subjects to treatment and no reliability on measures. Goldstein contended that AIT has no significant benefits to children with Autism over listening to music in a similar structured situation. In a 1998 policy statement by the America Academy of Pediatrics on Auditory Integration Training (Committee on Children with Disabilities, 1998), it was determined that currently available information did not support the claims of proponents that this treatment was efficacious. In addition, the New York State Department of Health Early Intervention Program (1999) review chose to recommend against the use of AIT, due to lack of proven efficacy. Below is a summary of the AIT research.

Table 7: Auditory Integration Training

Citation	Age	Diagnoses	Treatment	Design	Results
Muford, et al., 2000	9-13	N=21 Autistic 17 boys 4 girls IQ = 8-125 (5 dropped out)	10 hours AIT across 10 days, 2 30-minute sessions, 2x day with 3.5 hours between treatments. Control group used same times but S's wore nonfunctional headphones.	S's randomly assigned to treatment or control group. Raters blind to order of treatment. Crossover design. Measures: Vineland,	Some S's got worse in language and behavior. No benefits noted clinically or educationally. Could not replicate Rimland & Edelson study

				Reynell, Development Language Scale, Leiter, Aberrant Behavior Checklist, Direct Observation	
Bettison 1996	3-17	N=80 66 males 14 females Autism or Asperger's with mild to severe distress in the presence of some sounds	Exp. Group: AIT Modified music Control Group: Same music but not modified 20 sessions (Disc and Tracks were allocated to table of random numbers)	S's randomly assigned to treatment or control group Measures: Sound Sensitivity Questionnaire	
Gilberb, Johanson & Berlin, 1997	3-16	N=9 Autistic	AIT: 30 minute sessions for 10 days No controls	Measures: Questionnaires	No significant improvement
Edelson et al, 1999	4-39	N=19	AIT: 30 min periods over 10 days	Randomly assigned to treatment or placebo groups Measures: Questionnaires Audiometric testing	Treatment group showed decrease in problems behavior compared to placebo group on ABC rating on a 3 month follow up. At 6 months experimental group returned to baseline.
Rimland & Edelson, 1994	4-41	N=445 Autistic	AIT: 20-30 minute sessions over 10 days	Open trial No control group Pre/post measures: Observation Rating Scales	Sharp reductions in behavior problems from 1 month following treatment throughout 9 month follow up period
Zollweg, Palm, Vance, 1997	7-24	N=30 9 with Autism	AIT vs Unfiltered music 20/30 minute sessions over 10 days	Subjects were randomly assigned to treatment and treatment groups Measures: Questionnaires Observations	No differences between groups on questionnaires Both groups showed reductions in behavior problems

III. INTEGRATIVE/COMPLEMENTARY AND ALTERNATIVE MEDICINE (CAM) THERAPIES FOR CHILDREN WITH AUTISM

Recent literature review suggests that 30%-50% of children with Autism in the United States are using some form of Complementary and Alternative Medicine (CAM)(Levy & Hyman, 2003; Nickel, 1996).

a. Gluten and Casein Diets in Autism

There has been an increased interest in the elimination of gluten (wheat products) and casein (milk products) from the diet of children with Autism. A recent survey suggests that up to 15% of children with Autism adhere to these dietary restrictions. The gluten-free casein-free (GF/CF) diet is based on an “opioid excess” theory. In the 1970s, high levels of urinary opioid peptides among patients with Autism was demonstrated (Reichelt et al., 1991; Shattock et al., 1990). The source of the excess opioids is thought to be from dietary gluten and casein intake absorbed through an inflamed GI tract. Both gluten and casein are broken down in the GI tract as “opioid peptides,” that are rapidly absorbed into the bloodstream. Theoretically, if the GI tract is inflamed, opioid metabolites could be absorbed. Children with Autism may be vulnerable to increased absorption of opioid peptides, because many have evidence of increased gastrointestinal permeability (“leaky gut syndrome”) (D’Eufemia et al., 1996) due to gut inflammation, specifically “ileal lymphoid nodular hyperplasia” and colitis (Wakefield, et al., 1998).

The impact of excess opioid peptides in the urine on the development of autistic symptoms is unknown. Researchers who demonstrated excess opioid peptide in urine of these children have hypothesized that children with Autism behave in a manner consistent with “opioid intoxication,” including social withdrawal, sluggishness, lack of attention to surroundings and cognitive slowing. One study demonstrated that compliance with a gluten-free casein-free diet actually reduced the level of urinary opioid peptides among children with celiac disease (Stensrud & Reichelt, 1999). However, this has not been investigated among children with Autism and researchers did not attempt to link a decrease in opioid peptides among autistic or celiac patients to behavioral or developmental changes.

There is some preliminary data to suggest that elimination of gluten and casein from the diet of children with Autism may reduce symptoms. Lucarelli et al. (1995) first published a study in 1995 suggesting the potential efficacy of milk elimination diet in treating autistic symptoms. This group was studying the possible link between allergy and Autism and found that 36 children with Autism who eliminated milk products from the diet for eight weeks had significantly fewer autistic behaviors in five of seven categories on a standardized observational assessment of autistic symptoms. This study had significant limitations, however, including lack of an autistic control group, non-blinded

treatment, failure to control for other psychosocial interventions, e.g., behavior therapy, and lack of information regarding the use of other medications. Similarly, Knivesberg et al. (2002) conducted a small, randomized, single-blind clinical trial of gluten and casein elimination among 10 school aged children with Autism. The diet intervention group showed significant improvement in attention, social, and emotional functioning, as well as communication and cognition. This study was limited by a small sample size and the fact that it did not control for other interventions such as use of medications or behavior therapy. Critics of the study suggest that the increased attention and household structure needed to comply with the diet, combined with the use of more traditional therapies such as behavior modification, were not accounted for in the study and could have been responsible for the positive results.

Data assessing the safety and efficacy of the GF/CF diet in treating autistic symptoms is limited. Since the initial report by Lucarelli, one single-blind controlled trial of the gluten-free casein-free diet has been conducted among older school aged children. Whiteley et al. (1999) reported preliminary findings of some benefit of a gluten-free diet. Kidd (2002) summarized integrative treatment approaches in Autism and reported benefits in dietary restrictions (Bradstreet & Karzinel, 2002). However, to date there have been no published (in refereed journals) double-blind, placebo-controlled trials to demonstrate the effectiveness of this diet in young children with Autism. Additionally, a literature search found no published studies assessing the safety of this diet. This is of concern since many children with Autism already have limited diets based on their sensory aversion to certain types and textures of foods. Elimination of milk products potentially runs the risk of inadequate intake of protein, calcium, and other essential vitamins in the diet.

b. Omega-3 Fatty Acid Supplements in Autism

The essential fatty acids, alpha linoleic acid and linoleic acid, and their metabolic products, omega-3 and omega-6 fatty acids are important molecules in neuronal cell function. In the brain, Docohexanoic Acid (DHA) and Eicosopentanoic Acid (EPA) are the primary omega-3 fatty acids and arachadonic acid is the primary omega-6 fatty acid. These molecules affect neuronal signal transduction and activation of most neurotransmitters in the brain.

The correct balance of omega-3 to omega-6 fatty acids must be present for optimal cell functioning (Murphy, 1990). Thus, a diet high in omega-6 fatty acids, such as the modern Western diet, will form high amounts of arachadonic acid and its metabolic breakdown products lipooxygenases. These molecules actually promote inflammation and are implicated in numerous diseases such as heart disease and inflammatory conditions. The breakdown products of omega-3 fatty acids, DHA and EPA have anti-inflammatory properties and promote proper neuronal cell signaling and neurotransmission. The modern Western diet is relatively deficient in omega-3 fatty acids, leading to the hypothesis that dietary supplementation with the correct balance of essential fatty acids might lead to improved neuronal cell signaling and improved brain function.

There is evidence of reduced levels of omega-3 fatty acids in the serum of individuals with Autism and other neuropsychiatric disorders. Vancassel et al. (2001) has demonstrated that individuals with Autism have reduced serum levels of DHA compared to controls with mental retardation. A reduction in omega-3 fatty acid levels has also been described in adults with Schizophrenia (Peet et al., 1995) and Depression (Peet et al., 1998). Studies of omega-3 fatty acid supplementation in various psychiatric conditions have shown some benefits (for symptoms in schizophrenic patients [Fenton et al., 2001] and in depressed patients [Puri et al., 2002]). One study of children with Attention Deficit Hyperactivity Disorder symptoms showed a decrease in “general behavior problems” with essential fatty acid supplementation (Richardson & Puri, 2002). Despite reports that individuals with Autism have decreased levels of serum DHA, a review of the literature has found limited evidence of the effect of supplementation of individuals with Autism with omega-3 fatty acids on autistic symptoms. One case study of an 11 year old boy with Autism displayed “reduction of severe anxiety and ritualistic behavior” when given EFA supplementation (Johnson & Hollander, 2003). Similarly, Patrick and Salik (2005) reported the results of an open-label study of 18 children with Autism who were given the fish oil based supplement, ProEFA of omega-3 and omega-6 for 90 days, and showed “increases in their language and learning skills.

c. Vitamin B6 and Magnesium, and Dimethylglycine in Autism

Vitamin B6 in its active form of pyridoxal 5 phosphate (P5P) is an essential cofactor for a majority of metabolic pathways of neurotransmitters. Magnesium is required for a wide range of enzyme catalyzed metabolic pathways.

In 1998 and 2002 reviews, Rimland (1998; 2002) reported positive results with no adverse side effects from the combination of Vitamin B6 and Magnesium in several studies. However, criticism exists regarding the design, methodology, and outcome analyses for many of these studies. In 2004, Adams and Holloway (2004) reported that 11 children with Autism who participated in taking a supplement showed improvements in sleep and GI symptoms compared to nine children with Autism on placebo. However, the supplement was a compound that had a broad range of most vitamins and minerals. Also, there was limited assessment, limited statistical significance, and a small sample size. In 1995, Pfeiffer et al. (1995) conducted a methodology review and summary of outcomes and reports. It was concluded that in spite of some positive findings, researchers did not look at whether “B6-Mg treatment makes a real or meaningful difference in the lives of the research subjects.” Findling et al (1997) reported a study utilizing high doses of pyridoxine and magnesium in children with Autism with negative findings. However, Rimland criticized that study, in spite of its double-blind placebo-controlled design and strict Autism diagnostic assessments.

d. Secretin in Autism

Secretin is used in the diagnostic assessment of pancreatic gastrointestinal (GI) dysfunction. Interest in secretin as a treatment for Autism followed media reports of behavioral improvements in a few children with Autism who received the hormone during a GI diagnostic procedure. In a recent review by Esch and Car (2004), out of 17

studies with over 600 children, “12 of the 13 placebo controlled studies failed to demonstrate the differential efficacy of secretin”.

Summary

There are several current studies investigating dietary restrictions (GF/CF) and or supplements (EFAs) in Autism. Michelle Zimmer, MD and colleagues from Children’s Hospital of Pittsburgh and Western Psychiatric Institute and Clinic are conducting a study entitled, “Safety and Efficacy of Complementary and Alternative Medicine Treatments for Young Autistic Children (funded by the Emmerling Fund of the Pittsburgh Foundation). A larger funded study is in process at the University of Rochester Medical Center (NIH-STAART) with Susan Hyman, M.D., Patricia Rodier, Ph.D. and others. Also, the MIND Institute at University of California, Davis, has an ongoing GF/CF study.

Reviews of many integrative biological treatments are found in Kidd (2002), a book by Shaw (2002), and in DAN! Protocols and Annual Meeting Abstracts (Autism Research Institute, Bernard Rimland, Ph.D.). These are not necessarily unbiased reviews of methodology, design, assessments, outcomes analysis, etc. There are some profound comments in the Esch and Carr (2004) review on secretin which apply to the broader search for “promising but often unproven treatments in Autism,” and the following: “We must act responsibly to help parents and others evaluate the strengths and impact of yet unproven treatments. Above all, we must strive to advocate for rigorous scientific investigations that will define the therapeutic benefit of such treatments before anecdotal surrogates of those investigations wreak emotional and financial havoc on the lives of those we endeavor to help.”