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Report of the MADSEC Autism Task Force

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of the
MADSEC Autism Task Force**

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Report of the MADSEC Autism Task Force

MISSION STATEMENT

The MADSEC Autism Task Force will perform a detailed analysis of methodologies with which to educate children with autism. This analysis will focus upon the scope and quality of scientific research which objectively substantiates, or fails to substantiate, each method's effectiveness. Based upon the research analysis, the MADSEC Autism Task Force will make recommendations for the consideration of decision makers who are key to the intervention of children with autism.

STATEMENT OF PHILOSOPHY

The MADSEC Autism Task Force has concluded that an intervention for individuals with autism can be characterized in one of four ways:

- It may be objectively substantiated as effective based upon the scope and quality of scientific research.
- It may anecdotally show promise, but is not yet objectively substantiated as effective using controlled studies and subject to the rigors of good science.
- It may have been repeatedly subjected to the rigors of science, which leads numerous researchers to conclude that the intervention is not effective, may be harmful, or may lead to unintended consequences.
- It may be without scientific evaluation of any kind.

The MADSEC Autism Task force believes it is critical for professionals charged with making decisions about methodologies and services for children with autism to:

- obtain, know and understand the scientific support for each approach;
- recognize the difference between an approach that has been scientifically validated and one that has not.

In addition, the MADSEC Autism Task Force believes professionals endorsing a specific intervention for autism have an ethical responsibility to:

- accurately describe the research support of the intervention, or lack thereof;
- refrain from exaggerated claims of effectiveness when data supporting such claims do not exist;
- portray the method as experimental, if it is not yet validated as effective scientifically, and to disclose this status to key decision makers influencing the child's intervention.

Finally, it is important to note data exist in some cases which repeatedly lead to conclusions a particular methodology is ineffective or may be harmful. In such cases, the MADSEC Autism Task Force believes continued utilization of resources on these approaches is at best ethically questionable, and at worst a significant waste of time, energy, money, expertise, and a child's potential to live a fulfilling life in least restrictive settings.

ABSTRACT

Information and research pertaining to eight interventions routinely used for children with autism were evaluated and characterized as meeting one of four criteria:

- 1) The intervention is objectively substantiated as effective based upon the scope and quality of scientific research.
- 2) The intervention anecdotally shows promise, but is not yet objectively substantiated as effective using controlled studies and subject to the rigors of good science.
- 3) The intervention has been repeatedly subjected to the rigors of science, which leads numerous researchers to conclude the intervention is not effective, may be harmful, or may lead to unintended consequences.
- 4) The intervention may be without scientific evaluation of any kind.

The elements of sound, scientific research were explored. The definition and incidence of autism were presented, as well as the importance of early autism diagnosis and treatment. Conclusions, implications and recommendations were offered.

EXECUTIVE SUMMARY

Between 1991 and 1998, the number of Maine children classified by educators as having autism has increased from 42 to 304. This number is likely conservative: many children meeting the diagnostic criteria for autism may be classified as having speech/language disorder, behavior impairment, and/or as being multi handicapped. Educators and other interventionists must be adequately informed to:

- ensure services to children with autism are effective
- reduce litigation
- invest limited financial and practitioner resources wisely
- advocate for sufficient federal, state and local funding to meet service needs, and
- develop the professional human resource base necessary to meet service needs.

The importance of early, intensive intervention for children with autism cannot be overstated. Numerous studies have concluded outcomes are substantially more positive when the children begin receiving effective, intensive intervention as early as possible in life (including the potential to recover normal functioning such that an autistic child may become virtually indistinguishable from his peers) (eg Fenske, et al, 1985; Lovaas, 1987; Maurice, 1993; Perry, Cohen & DeCarlo, 1995). Furthermore, early, intensive, effective intervention offers the hope of significant cost/benefit (Jacobson, Mulick & Green, 1996).

In contrast, it is likely 90% of children who do not receive effective early intervention will require special or custodial care throughout their lives. This is estimated to cost the US over \$13 billion a year (FEAT, 1996).

Based upon a thorough examination of numerous methodologies considered as interventions for children with autism, the MADSEC Autism Task Force has characterized the interventions reviewed as follows:

- **Substantiated as effective based upon the scope and quality of research:**
Applied behavior analysis. In addition, applied behavior analysis' evaluative procedures are effective not only with behaviorally-based interventions, but also for the systematic evaluation of the efficacy of *any* intervention intended to affect individual learning and behavior. ABA's emphasis on functional assessment and positive behavioral support will help meet heightened standards of IDEA '97. Its emphasis on measurable goals and reliable data collection will substantiate the child's progress in the event of due process.
- **Shows promise, but is not yet objectively substantiated as effective for individuals with autism using controlled studies and subject to the rigors of good science:**
Auditory Integration Training, The Miller Method™, Sensory Integration, and TEACCH.
- **Repeatedly subjected to the rigors of science, which leads numerous researchers to conclude the intervention is not effective, may be harmful, or may lead to unintended consequences:** Facilitated Communication.

- **Without scientific evaluation of any kind:**
Greenspan's DIR/"Floor Time," Son-Rise.

Implications

It is neither the mission nor the intent of the MADSEC Autism Task Force to propose public policy regarding effective interventions for children with autism. Rather, the Task Force seeks to provide detailed information to help families, educators and other service providers make informed decisions.

The thoughtful analysis offered in this document may provoke increased demand for certain autism interventions, such as applied behavior analysis. Child Development Services may also experience added pressure for early identification of children with autism, as well as immediate, intensive, effective intervention.

Practitioners of applied behavior analysis require specialized training in addition to that normally gained by professionals specializing in behavior impairment, special education, child development or psychology. Increased demand for applied behavior analysis will precipitate the need for professional development resources to ensure ABA practitioners have sufficient and appropriate training.

Recommendations

- 1) Develop an aggressive plan to encourage screening of every child for autism as part of routine pediatric care.
- 2) Improve data collection systems to more accurately determine the number of Maine children who meet the diagnostic criteria for autism, independent of or in addition to other impairments.
- 3) Justify and seek additional funding from the Maine State Legislature for increased early autism identification and intervention.
- 4) Ensure services for children with autism are based upon scientifically validated procedures.
- 5) Ensure that services to children with autism include systematic instruction procedures focusing on both the acquisition of skills, and the decrease/elimination of interfering behaviors.
- 6) Require ongoing evaluation of autism interventions using controlled studies and subject to the rigors of good science. Ongoing evaluation should minimally include a credible method of evaluation, and criteria for determining whether to terminate or continue the intervention.
- 7) Identify and recruit qualified behavior analysts from within and outside of Maine as required to meet current service needs.
- 8) Convene a Task Force charged with developing resources sufficient to meet and support the demand for applied behavior analysis.

DEFINITION OF AUTISM

The definition of autism used in this document is based on the diagnostic criteria provided in the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders - Fourth Edition* (DSM - IV.)

Autism is included under DSM-IV's pervasive developmental disorders. This is a category of disorders in which many basic areas of infant and child psychological development are affected at the same time, and to a severe degree.

Autistic disorder has three major hallmarks: qualitative impairment in social interaction, qualitative impairment in communication, and restricted, repetitive and stereotypical patterns of behavior, interests, and activities. Onset in delays is very early, prior to three years of age.

To meet DSM-IV diagnostic criteria for autism, children will display impairment in social interaction in at least two ways, impairment in communication in at least one way, and restricted, repetitive and stereotypical patterns of behavior, interests and activities in at least one way.

According to DSM-IV, impairment in social interaction is manifested in at least two of the following ways:

- 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 achievement with other people;
- d) lack of social or emotional reciprocity.

Impairment in communication is 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;
- b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain conversation with others;
- c) stereotyped and repetitive use of language or idiosyncratic language, and
- d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level.

Restricted, repetitive and stereotyped patterns of behavior, interests and activities are manifested by at least one of the following:

- encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity of focus;
- apparently inflexible adherence to specific, non-functional routines or rituals;
- stereotyped and repetitive motor mannerisms, such as hand or finger flapping, or complex whole body movements;
- persistent preoccupation with parts of objects.

(DSM-IV, 1994).

Autism and PDD: What's the Difference?

Pervasive Developmental Disorders (PDD) as defined in the *American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders—Fourth Edition* (DSM-IV) is a category of disorders incorporating extreme developmental abnormalities with onset in the first three years of life. Pervasive Developmental Disorder represents a distortion in basic development with characteristic features including:

- Severe and pervasive impairment in reciprocal social interaction;
- Severe and pervasive impairment in communication skills; and
- Presence of stereotyped behavior, interests and activities.

“Basic psychological functions such as attention, mood, intellectual functioning and motor movement are affected at the same time, and to a severe degree.” (Rapoport & Ismond, 1996).

Within the broad classification of PDD are five subtypes: Autistic Disorder, Asperger's Disorder, Rett's Disorder, Childhood Disintegrative Disorder and PDD-Not Otherwise Specified (PDD-NOS).

Autistic Disorder is the best studied of the PDD subtypes. To be diagnosed as autistic, children must display impairment in social interaction in at least two ways, impairment in communication in at least one way, and restricted, repetitive and stereotypical patterns of behavior, interests and activities in at least one way. (See **Definition of Autism**.)

Asperger's Disorder is characterized by severe and sustained impairment in social interaction combined with restricted, repetitive and stereotyped patterns of behavior, interests and activities (DSM-IV, 1994). This disorder differs from autism in that “few clinically significant delays in language or cognitive development are apparent, and self-help and adaptive behaviors often appear normal.” (Rapoport & Ismond, 1996).

Rett's Disorder is the only subtype of PDD which occurs exclusively in females. In this disorder, development seems normal through the first five months of life, followed by deceleration of head growth, loss of previously acquired purposeful hand skills with subsequent development of stereotyped hand movements, loss of social engagement, appearance of poorly coordinated gait or trunk movements, and severely impaired expressive and receptive language, (DSM-IV, 1994).

Childhood Disintegrative Disorder is characterized by development that appears normal through the first two years of life. Following this, abnormalities develop in at least two of the following areas: social interaction, communication, and restricted, repetitive, stereotyped patterns of behavior, interests, and activities. In addition, there is clinically significant loss of previously acquired skills (before age 10), in at least two of the following areas: expressive or receptive language, social skills or adaptive behavior, bowel or bladder control, play, and motor skills. (DSM-IV, 1994).

The category of PDD-NOS is used when there is severe and pervasive impairment in the development of reciprocal social interaction and verbal and nonverbal communication skills, or

when stereotyped behavior, interests and activities are present, but symptoms do not meet the criteria for other disorders. (DSM-IV, 1994).

Typically, Pervasive Developmental Disorders are extremely incapacitating, and their symptoms are chronic and lifelong (although this is less the case for Asperger's Disorder). "Factors considered most important for determining prognosis are IQ levels, and development of social and language skills" (Rapoport & Ismond, 1996). Identification of variables that predict outcomes reliably continue to undergo intense study within the scientific community. Given the chronic nature of PDD, however, long-term treatment is typically required.

Catherine Maurice is a mother who recovered her daughter and son from autism in the 1980s (Perry, Cohen & DeCarlo, 1995; Maurice, 1993), and subsequently wrote the book *Let Me Hear Your Voice*. Exploring the impact of distinctions between clinical definitions of PDD subtypes on children and families, Maurice wrote:

"Most parents I've come to know don't pay too much attention, at least after a while, to trying to figure out these various terms. They're smart enough to know that whether their child gets a "PDD" or an "infantile autism," they had better treat the problem with the same urgency. But other parents, unfortunately, are led to believe, or choose to believe, that PDD means "not very severe." I will never forget a mother's sigh of relief after three harrowing weeks of diagnosis for her young son: "He's OK!" she told me in a phone conversation. "All he has is PDD!" To her, it seemed to mean he was not autistic and therefore would be fine, that he was merely in some sort of passing phase. I suggest that any parent who hears the statement "He's not autistic, he's only PDD" ask the professional pronouncing these words to explain the difference in prognosis between the two labels" (Maurice, 1993).

What Causes Autism?

According to the Autism Society of Maine, "Medical researchers are exploring different explanations for the various forms of autism. Although one specific cause is not known, current research links autism to biological or neurological differences in the brain. MRI (Magnetic Resonance Imaging) and PET (Positron Emission Tomography) scans show abnormalities in the structure of the brain, with significant differences within the cerebellum. In some families there appears to be a pattern of autism or related disabilities which suggest there may be a genetic basis to the disorder, although at this time no one gene has been linked to autism."

"Several older theories about the cause of autism have now been proven false. Autism is not a mental illness. Children with autism are not unruly kids who choose not to behave. Autism is not caused by bad parenting. Furthermore, no known psychological factors in the development of the child have been shown to cause autism" (Autism Society of Maine, Brochure).

Other research concluding autism is not caused by bad parenting includes McAdoo & DeMeyer, 1978; Koegel, Schreibman, O'Neill & Burke, 1983; Sigman & Mundy, 1989; and Sigman & Ungerer, 1984.

Klinger and Dawson point out,

"Historically, it was believed that parents of children with autism were overly intellectual, cold-

hearted, and had a limited interest in other people including their spouses and children (Kanner, 1943; Bettelheim, 1967). Bettelheim (1967) proposed that in response to rejecting parents, children with autism withdrew from social interaction and became self-sufficient. Until the mid 1970s, treatment regimes involved helping parents, usually mothers, to become less rejecting of their children. However, these initial hypotheses regarding the etiology of autism were not supported by empirical research conducted in the 1970s and 1980s. McAdoo and DeMeyer (1978) and Koegel, Schreibman, O'Neill and Burke (1983) administered the Minnesota Multiphasic Personality Inventory to parents of children with autism. These parents scored within the normal range on all of the personality measures. Additionally, parents of children with autism and parents of children without disabilities reported similar levels of marital satisfaction and family cohesion."

Klinger and Dawson also explore attachment:

"It was originally assumed that children with autism fail to bond with their parents. Some even suggested that they are not able to discriminate between familiar and unfamiliar adults (Cohen, Paul & Volkmar, 1987). However, empirical evidence suggests that children with autism do show differential responses to their caregivers compared to unfamiliar adults (Sigman & Mundy, 1989; Sigman & Ungerer, 1984). . . Secure attachment quality in autism approaches the rates seen in normally developing populations. Taken together, these findings suggest that autism does not result from a global impairment in the ability to form attachments. . . (Rogers, et al, 1993; Sigman & Mundy, 1989)."

References/Definition of Autism

American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders (4th ed.)*. Washington, DC: Author.

Autism Society of Maine. (No date). Autism. [Brochure]. Gardiner, ME: Author.

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Perry, R., Cohen, I., & DeCarlo, R. (1995). Case study: Deterioration, autism, and recovery in two siblings. *Journal of the American Academy of Child and Adolescent Psychiatry*, 34, 232 - 237.

Rapoport, J.L. & Ismond, D.R. (1996). *DSM-IV training guide for diagnosis of childhood disorders*. New York: Brunner/Mazel.

INCIDENCE

According to the National Institutes of Health, the incidence of autism now ranges from one in 500 births to one in 200, up from previous estimates of 1 in 666 (15 in 10,000). It is unknown whether this alarming increase is due to an actual increased incidence, expanded definition in DSM-IV, or more vigilant diagnosis. According to the Autism Society of Maine, "Autism is four times more prevalent in boys than girls, and knows no racial, ethnic or social boundaries. Family income, lifestyle and educational levels do not affect the chance of autism's occurrence" (Autism Society of Maine, Brochure).

According to the Maine Department of Education (1997), 304 Maine children between the ages of three and 20 have autism. However, it is possible many Maine children who meet the diagnostic criteria for autism have been classified by educators as having speech/language disorder, behavior impairment, and/or as being multi handicapped. Therefore, the figure of 304 is conservative.

Since 1991, the rate of Maine students identified by educators as having autism has increased dramatically:

Year	Number of Students with Autism Identified by Educators
1991 - 1992	42
1992 - 1993	63
1993 - 1994	99
1994 - 1995	108
1995 - 1996	158
1996 - 1997	220
1997 - 1998	304
1998 - 1999	382

References/Incidence

Autism Society of Maine. (No date). Autism. [Brochure]. Gardiner, ME: Author.

Maine Department of Education, Child Count, 1991 - 1998.

*Autism was first included as a category in the Maine Department of Education Child Count on December 1, 1991, for the 1991 - 92 school year.

THE IMPORTANCE OF EARLY AUTISM DIAGNOSIS AND TREATMENT

Currently, the importance of early diagnosis and treatment is well established amongst diverse groups of professionals (Fenske, et al, 1985; Lovaas, 1987; Maurice, 1993; Perry, Cohen & DeCarlo, 1995). Researchers are finding “it may be the case that there is a “critical period” during which the young, developing brain is very modifiable. For some children with autism, the repeated, active interaction with the physical and social environment that is ensured by intensive behavior analytic treatment may modify their neural circuitry before it goes too much awry, correcting it before autism becomes permanent (Lovaas & Smith, 1989; Perry, Cohen & DeCarlo, 1995.) At this point in time, of course, these are merely plausible speculations that remain to be investigated in scientific studies.” (Green, 1995).

It is likely 90% of children with autism who do not receive effective early intervention will require special or custodial care throughout their lives. This is estimated to cost the US over \$13 billion a year (Families for Early Autism Treatment, Video).

References/Early Intervention

Families for Early Autism Treatment (FEAT). “Doctor, My Child Doesn’t Talk:” The Importance of Early Autism Diagnosis. [Video]. Available: FEAT, PO Box 255722, Sacramento, CA 95865-5722 (916) 843-1536.

Fenske, E. C., Zalenski, S., Krantz, P. J., & McClannahan, L. E. (1985). Age at intervention and treatment outcome for autistic children in a comprehensive intervention program. *Analysis and Intervention in Developmental Disabilities*, 5, 49 - 58.

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Lovaas, O. I. (1987). Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology*, 55, 3 - 9.

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“TEACHER, MY CHILD DOESN’T TALK:” SCREENING CHILDREN FOR AUTISM

According to a survey conducted by Families for Early Autism Treatment (FEAT), these are the five most common concerns parents described prior to diagnosis of autism by a qualified professional:

- 1) Lack of speech, and/or had words and lost them.
 - 2) Child seems deaf.
 - 3) Child does not make eye contact with parent or care giver.
 - 4) Child has unusual, odd behaviors including severe tantrums. The child may also be self injurious, difficult to control, and engage in self stimulation.
 - 5) Child ignores or does not play with other children.
- (FEAT, 1997)

CHAT, the Checklist for Autism in Toddlers, has demonstrated strong effectiveness in predicting which children will ultimately receive a diagnosis of autism (The British Journal of Psychiatry, 1996). Parents, care givers and educators can ask themselves:

- 1) Does your child enjoy being swung, bounced on your knee, etc?
- 2) Does your child take an interest in other children?
- 3) Does your child like climbing on things, such as up stairs?
- 4) Does your child enjoy playing peek-a-boo, or hide-and-seek?
- 5) Does your child ever *pretend*, for example, to make a cup of tea using a toy cup and teapot, or pretend other things (pouring juice)?
- 6) Does your child ever use his/her index finger to point, to *ask* for something?
- 7) Does your child ever use his/her index finger to point, to *indicate interest* in something?
- 8) Can your child play properly with small toys (eg cars or blocks) without just mouthing, fiddling with, or dropping them?
- 9) Does your child ever bring objects over to you (parent), to *show* you something?

CHAT also includes more detailed observational assessment that can be conducted by a professional. (See appendix for complete CHAT screening tool.)

The Childhood Autism Rating Scale (CARS) is also a useful instrument for children ages two and over that can reliably distinguish children with autism spectrum disorders from children with other developmental disorders, as well as distinguish amongst levels of severity within the autism range. This instrument can be used through observation, reviewing charts and records, and/or interviews. It is comprised of fifteen domains: relating to people, imitation, emotional response, body use, object use, adaptation to change, visual response, listening, taste/smell/touch response and use, fear or nervousness, verbal communication, nonverbal communication, activity level, level and consistency of intellectual responses, and general impressions. A four-point scale provides ratings on a continuum from within normal limits (1) to severely abnormal (4). Total scores then lead to categorization from non-autistic, to mild autism, to moderate autism, to severe autism.

CARS is described by its authors as “an initial aid in the classification process” (Schopler, Reichler & Rothen-Renner, 1988). It is constructed to be immediately useable with minimum

training by professionals from a wide variety of disciplines. Reliability and validity are considered acceptable. A constraint of this instrument is that it incorporates a range of symptoms with no weighting, yet some symptoms are clearly more diagnostic than others. Reliability and validity data also need to be updated. CARS can be obtained from Western Psychological Services, 12031 Wilshire Boulevard, Los Angeles, CA 90025-1251.

Parents and professionals who suspect a child may have autism should *immediately* alert the child's physician. Children under five should be referred to Child Development Services. Children five and over should be referred to local public schools. Based upon the results of initial screenings, the child may be referred to a psychologist, psychiatrist, or one of five developmental evaluation clinics (DECs) throughout Maine for a definitive diagnosis (see appendix for list).

Some children with autism have complex biobehavioral issues including seizure activity, self injury, tantrums, aggression, and property destruction. Combined with severe deficits in functional communication, these behaviors may require inpatient assessment.

Currently there is no inpatient biobehavioral unit (BBU) in Maine capable of supporting extended, comprehensive assessment and treatment of children with severe behavior disorders secondary to developmental disabilities and chronic illness. In fact, only four BBUs of varying size and service exist in the United States (see appendix for list).

Early diagnosis leading to effective, early intervention is critical to the child's outcome. If in doubt, refer!

References/Screening Children for Autism

The British Journal of Psychiatry, (1996), 168, 158 - 163; The British Journal of Psychiatry, (1992), 161, 839 - 843.

"Doctor, My Child Doesn't Talk:" The Importance of Early Autism Diagnosis. (Pamphlet) Families for Early Autism Treatment (FEAT), PO Box 255722, Sacramento, CA 95865-5722 (916) 843-1536.

Schopler, E., Reichler, R. J., & Rochen-Renner, B. (1988). Childhood Autism Rating Scale, Western Psychological Services.

**PROCESS:
HOW DID THE MADSEC AUTISM TASK FORCE REACH ITS CONCLUSIONS?**

By May of 1997, it was becoming apparent to MADSEC that many school districts were in need of a research-based review of autism interventions to help determine which methods are most effective. MADSEC convened a task force comprised of special education directors, CDS staff, special education teachers, psychologists, a representative of the Autism Society of Maine, a representative of the Maine Department of Education, and parents of children with autism. The task force further benefitted from the adjunct participation of two attorneys specializing in special education law: one that routinely represents school districts, and one that routinely represents parents.

Monthly meetings began in September, 1997. Over the first two months, the task force determined the criteria by which interventions would be evaluated. After much discussion, it was determined interventions would be evaluated based upon the scope and quality of science substantiating the method's effectiveness.

The task force then compiled a list of as many methodologies to consider as we could find, using professional journals, Internet searches, autism literature, and referrals. It was determined that dietary and pharmacological interventions did not fall within the scope of likely "educational" methodologies, and therefore were not evaluated by this group.

Key leaders in each methodology were identified, and invited to present to the MADSEC autism task force. Along with a comprehensive overview of the guest's area of expertise, each presenter was instructed to review the scope and quality of research substantiating the intervention's effectiveness *with children with autism*. At the conclusion of the presentation, task force members were given the opportunity to ask questions.

In addition to presentations, the task force collected and reviewed innumerable documents specific to the intervention under study. These included narratives, books, films, and promotional materials, as well as scientific studies. In that these were collected largely by submission by task force members, it could be argued that materials under evaluation were not selected at random. To further pursue objectivity in determining the scope of scientific support for each methodology, the task force secured the services of a University of Southern Maine student nearing completion of a Masters degree in Special Education.

The student ran Internet and database searches using a range of search terms for each methodology. Results were then compiled by the student, who also offered some preliminary analysis of the scientific merit of the results for the task force's review, discussion and revision.

Throughout the year and a half the task force conducted its work, there was considerable discussion among members probing controversial issues, and re-direction to the mission statement.

By September of 1998, a group of task force members began drafting portions of this document, while task force study and presentations by key leaders continued.

In January, 1999, consensus was reached on conclusions.

Presentations to MADSEC Autism Task Force

Date	Domain	Presenter	Affiliation
10/17/97	Research	Libby Cohen, PhD	University of Southern Maine
1/30/98	Facilitated Communication	Alan Kurtz, M Ed	Center for Community Inclusion
2/13/98	Applied Behavior Analysis	Gina Green, PhD	New England Center for Children
4/10/98	Miller Method™	Arnold Miller, PhD	Language and Cognitive Development Center
10/9/98	Auditory Integration Training	Janis Ames, MA, CCC-SLP	Auditory Integration Training Services
11/13/98	Sensory Integration	Judy Kimball, PhD	University of New England

RESEARCH

What is Research?

According to Fraenkel and Wallen (1990), there are eight types of educational research:

- 1) True Experimental: two or more groups, whose members have been randomly assigned, are compared before and after one or more group is given a treatment or intervention.
- 2) Quasi-experimental: two or more groups whose members are not randomly assigned are compared after one or more groups receive a treatment or intervention.
- 3) Correlational: within one group, individual scores on one attribute are compared with scores on another attribute.
- 4) Causal-Comparative: two or more groups are compared, to understand the causes or consequences of the differences between them.
- 5) Survey: information is collected to describe characteristics of a group.
- 6) Qualitative: an in-depth description of a group.
- 7) Historical: information from the past is analyzed to better understand what took place.
- 8) Content Analysis: the contents of a communication are analyzed to look for patterns or relationship.

True experimental research is the most effective design for obtaining information that can be considered scientifically accurate (Fraenkel and Wallen, 1990; Cohen, 1998). This type of research can be done two ways:

- With groups
- Using single-subject or single case design

Good research follows a standard format. To help investigators decide whether work under consideration is truly experimental, the following was developed by Libby Cohen, PhD, University of Southern Maine/Gorham:

- Review the literature: is there a review of the literature? Is it comprehensive, or restricted to a few specific citations?
- Does the research state the purpose, research question or hypothesis? If so, is this educationally relevant to you?
- Methodology (the research design): does it describe the subjects? Are there two or more groups randomly assigned? Are the instruments used to measure the treatment valid and reliable? Does the procedure make educational sense? Does it leave anything out?
- Results: Is there a data analysis? Do the findings seem to be supported by the data?
- Conclusions and recommendations: Do these follow from the data?

Why is Research Important?

Special Education Directors are responsible for assuring quality educational programs for all students with disabilities requiring special education services. Quality programs should have a research base to show they are appropriate for the student.

Sometimes an intervention which shows promise may not have the benefit of a research base, but it may appear to be appropriate for the student. In those cases, the professional who will coordinate an intervention that has not been scientifically validated should be required to define expected outcomes in a measurable format. This begins with gathering data prior to the intervention (baseline data). The Team should determine a reasonable length of time during which the intervention, if it is effective, will show progress. Objective data should be collected throughout the intervention.

It is critical that data are *objective*, not *subjective*. “I see progress” is subjective. An objective report of progress is “Given 10 objects, and the cue “Show me [object], Student is able to identify 8 objects correctly by pointing, with 0 prompts, with 90% accuracy, over 3 consecutive sessions. This contrasts with 0 objects at baseline.” (It is important to note there are more advanced techniques to ensure objective data is being accurately collected, as well, which are beyond the scope of this report.)

Educators should be aware that more than one variable may affect a student’s performance under any methodology, positively or negatively. These may include a new reading program, family change, new teacher, or a move to a new neighborhood. Consequently, if necessary, there are also techniques to determine whether the student’s progress, or lack thereof, is related to the intervention, or other factors.

While this may be a new way of thinking, the Individualized Education Plan (IEP) offers a familiar way to put it into practice. The IEP can be viewed as a single subject design. The student must first be evaluated. This constitutes baseline data, reported in the Present Levels of Performance section. Where the intervention takes place is stated under Least Restrictive Placement. The type of service and frequency of the intervention are documented under Services. Attempts at controlling outside variables can be reported under Accommodations for Regular Education. Finally, the Goals and Objectives state the specific intervention, the benchmarks for measuring progress, schedule of progress assessment, and the method with which to objectively measure assessment.

There is considerable incentive for Special Education programs to demonstrate factual data collection and objective documentation of progress. Throughout the United States, hearing officers are criticizing IEPs as relying upon too much anecdotal record keeping. This was seen in two recent Maine decisions involving children with autism. 26 IDELR 96 involved a Portland School System child diagnosed with PDD and a seizure disorder. The parents challenged the current IEP, as well as those for the two previous years. Notwithstanding procedural violations surrounding the IEPs, the hearing officer ordered the school to provide the methodology requested by the family. This was based upon the hearing officer’s determination that the district had failed to show sufficient evidence of educational progress. In fact, the hearing officer appeared to emphasize the school’s over dependence upon “anecdotal descriptions” in her ruling. Citing lack of clear starting points of ability, evaluation of goals and objectives, and benchmarks of progress, the hearing officer clearly felt the school could not provide defacto evidence of progress.

A similar ruling was reached in another Maine case involving MSAD #28, 28 IDELR 786. In this

case, the hearing officer found the school's reliance upon anecdotal descriptions of progress to be insufficient. She ordered an out of state program requested by the family, which relied heavily on charting progress around the clock.

Resources

"While one can consult experts, review books and articles, question or observe colleagues with relevant experience, examine one's own experience in the past, or even rely on intuition, the answers they provide are not always reliable." (Fraenkel and Wallen, 1990.)

Research or information is perhaps most commonly found through a university library. Unfortunately, unless the investigator is a student, access to research will be limited to the journals and books on site. Access to databases including ERIC, Psychlit, URSUS, Medline, and Carl Undercover is limited to CD-ROM-based computers in the library. However, MADSEC has learned from one USM reference professional that access may soon become more widely available.

For now, however, access can be gained by enlisting the assistance of a graduate student or professor to assist with research. There may be some charge. Alternatively, service providers may have the resources to conduct a search. This is an especially prudent step if the provider has proposed an intervention about which there is little known, or if it is controversial.

"Information Exchange" is a service of the Maine State Library that provides access to the latest research and information to all K - 12 educators in Maine. The Maine State Library has access to two databases: ERIC, and The Maine Resource Bank, which was developed and is maintained by the Information Exchange. (See appendix for more information).

Perhaps the most accessible method of gaining *information*, and to some degree *research*, is the World Wide Web on the Internet. Note emphasis on the word *information*. Many www sources offer information—not research. In that the Internet is unregulated, the accuracy of information posted on the net lies entirely within the credibility of the web page owner.

Ongoing Research: How Can It Help?

The MADSEC Autism Task Force has concluded continuing research using rigorous research protocols and standards of good science is critical to the ability of educators and other interventionists to improve the lives of children with autism. Without the research of years past, educators and treatment professionals would not be able to help children with autism to the degree we can today. Without ongoing research, we will not be able to answer the many burning questions that still remain about intervention for autism, such as:

- How much intervention is optimal?
- What variables predict outcomes reliably?
- Are there more effective ways to teach children who are not fast responders, or who have difficulty with spoken language?
- Are brains in fact changing as a result of intensive, effective intervention?

“Society’s decision about how to best serve the needs of individuals with autism should not be framed in terms funding research vs. funding treatments of known efficacy. Rather, Society needs to invest in treatments of known efficacy, withdraw funding of treatments known to be ineffective or harmful, and invest in *sound, scientific* research rather than in the pseudoscience that is rampant in autism today” (Gina Green, PhD, personal communication to Perry, 4/9/97).

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APPLIED BEHAVIOR ANALYSIS

Databases Searched	Dates	Search Terms
MEDLINE [®] Advanced	January 1998 - October 1998	'autism and treatment'; 'autism and behavioral intervention'; 'autism and behavioral treatment'; 'applied behavior analysis and autism'; 'autism and systematic instruction'; 'autism and discreet trial training'.
MEDLINE [®] Advanced	1996 - 1997	
MEDLINE [®] Advanced	1994 - 1995	
MEDLINE [®] Advanced	1992 - 1993	
MEDLINE [®] Advanced	1990 - 1991	
MEDLINE [®] Advanced	1988 - 1989	
PsychINFO	1996 - September 1998	
PsychINFO	1993 - 1995	
PsychINFO	1989 - 1992	

Search Yield: Under the search terms 'autism and treatment', 1028 records. These included a variety of methodologies and single case designs. Search was narrowed to 'autism and behavioral intervention,' and 'autism and behavioral treatment,' et al (see above) , resulting in 254 records.

Original search results available at the MADSEC office upon request.

Notes: Additional information for description and literature review was collected from research reviews (Hingtgen & Bryson, 1972; DeMeyer, Hingtgen & Jackson, 1981; Baglio, Benavidiz, Compton, et al, 1996); references within search yield; presentation to the MADSEC Autism Task Force by Gina Green, PhD, Director of Research at the New England Center for Children/Southborough, MA, and numerous informational documents gathered by Task Force members.

Description of Applied Behavior Analysis

Applied behavior analysis (ABA) is the science of human behavior. Over the past 30 years, several thousand published research studies have documented the effectiveness of ABA across a wide range of:

- populations (children and adults with mental illness, developmental disabilities and learning disorders)
- interventionists (parents, teachers and staff)
- settings (schools, homes, institutions, group homes, hospitals and business offices), and
- behaviors (language; social, academic, leisure and functional life skills; aggression, self-injury, oppositional and stereotyped behaviors)

Applied behavior analysis is the process of systematically applying interventions based upon the principles of learning theory to improve socially significant behaviors to a meaningful degree, *and to demonstrate that the interventions employed are responsible for the improvement in behavior* (Baer, Wolf & Risley, 1968; Sulzer-Azaroff & Mayer, 1991).

“Socially significant behaviors” include reading, academics, social skills, communication, and adaptive living skills. Adaptive living skills include gross and fine motor skills, eating and food preparation, toileting, dressing, personal self-care, domestic skills, time and punctuality, money and value, home and community orientation, and work skills.

ABA methods are used to support persons with autism in at least six ways:

1. to *increase* behaviors (eg reinforcement procedures increase on-task behavior, or social interactions);
2. to *teach new skills* (eg, systematic instruction and reinforcement procedures teach functional life skills, communication skills, or social skills);
3. to *maintain behaviors* (eg, teaching self control and self-monitoring procedures to maintain and generalize job-related social skills);
4. to *generalize* or to transfer behavior from one situation or response to another (eg, from completing assignments in the resource room to performing as well in the mainstream classroom);
5. to *restrict* or narrow conditions under which interfering behaviors occur (eg, modifying the learning environment); and
6. to *reduce* interfering behaviors (eg, self injury or stereotypy).

ABA is an objective discipline. ABA focuses on the reliable measurement and objective evaluation of observable behavior.

Reliable measurement requires that behaviors are defined objectively. Vague terms such as anger, depression, aggression or tantrums are redefined in observable and quantifiable terms, so their frequency, duration or other measurable properties can be directly recorded (Sulzer-Azaroff & Mayer, 1991). For example, a goal to reduce a child’s aggressive behavior might define “aggression” as: “attempts, episodes or occurrences (each separated by 10 seconds) of biting, scratching, pinching or pulling hair.” “Initiating social interaction with peers” might be defined as: “looking at classmate and verbalizing an appropriate greeting.”

ABA interventions require a demonstration of the events that are responsible for the occurrence, or non-occurrence, of behavior. ABA uses methods of analysis that yield convincing, reproducible, and conceptually sensible demonstrations of how to accomplish specific behavior changes (Baer & Risley, 1987). Moreover, these behaviors are evaluated within relevant settings such as schools, homes and the community. The use of single case experimental design to evaluate the effectiveness of individualized interventions is an essential component of programs based upon ABA methodologies. This is a process that includes the following components:

- a) selection of interfering behavior or behavioral skill deficit

- b) identification of goals and objectives
- c) establishment of a method of measuring target behaviors
- d) evaluation of the current levels of performance (baseline)
- e) design and implementation of the interventions that teach new skills and/or reduce interfering behaviors
- f) continuous measurement of target behaviors to determine the effectiveness of the intervention, and
- g) ongoing evaluation of the effectiveness of the intervention, with modifications made as necessary to maintain and/or increase both the effectiveness and the efficiency of the intervention.

This process incorporates all of the features that constitute a favorable and accountable approach to behavior change (Sulzer-Azaroff & Mayer, 1991).

Emerging Trends in ABA

Emerging trends within the field of ABA include positive behavioral support, functional assessment, and functional communication training.

Positive behavioral support refers to the broad process of assisting individuals to acquire adaptive, socially-meaningful behaviors, and to overcome patterns of destructive, maladaptive and stigmatizing behaviors (Koegel, Koegel & Dunlap, 1996). ABA-based methods of instruction are emphasized within positive behavioral support interventions to increase pro-social behavior, while concurrently decreasing maladaptive behaviors.

A primary goal of positive behavioral supports is to teach functional skills as a replacement for problem behavior. Positive behavioral support plans typically involve changing existing environments in a manner that makes problem behaviors irrelevant, ineffective and inefficient (Horner, O'Neill & Flannery, 1993). This usually involves changing a variety of aspects of the environment. Positive behavioral support plans often include changing many environmental variables in concert (eg physical setting, task demands, curriculum, instructional pace, instruction of new skills, and individualized reinforcement) (Horner, Vaughn, Day & Aard, 1996).

O'Neill, et al (1997) reported that the heart of a behavior support plan lies in the extent to which the plan:

- a) is based upon the results of functional assessments
- b) is consistent with fundamental principles of behavior
- c) provides a good conceptual "fit" with the values, resources and skills of all the people in the setting, and
- d) includes ongoing evaluation to determine the effectiveness of the intervention.

Another emerging trend in applied behavior analysis is functional assessment. Functional assessment is the process for gathering information that can be used to maximize the effectiveness and efficiency of behavioral support interventions (O'Neill, et al, 1997). Five primary outcomes of the functional analysis process are:

- 1) a clear description of problem behaviors

- 2) identification of the events, times and situations that predict problem behavior
- 3) identification of the consequences that maintain behavior
- 4) development of summary statements or hypotheses specifying the motivating function of behavior, and
- 5) collection of direct observation data that support the summary hypothesis (O'Neill, et al, 1997).

Functional assessment is a rigorous, empirically-based method of evaluation (Steege, in press). Several studies have demonstrated that interventions based on the results of comprehensive functional assessments have a much higher probability of being effective than those interventions based upon traditional forms of assessment (eg norm-referenced, intellectual/achievement/behavioral, projective personality, anecdotal observations and unstructured interviews) (Repp, Felce & Banton, 1988; Durand, Crimmins, Caulfield & Taylor, 1989; O'Neill, et al, 1997). Moreover, while traditional forms of assessment may be useful for purposes of diagnosis or for making placement decisions, the results of these types of assessments have not been demonstrated to be particularly useful in designing interventions. In contrast, the results of functional assessments are used as the basis for developing individualized interventions (Steege, in press).

Functional assessment is applicable not only to individuals with developmental disabilities. There is a growing body of research demonstrating the utility of functional assessment procedures with students evidencing a wide range of handicapping conditions (Steege & Northup, 1998). Furthermore, functional assessment frequently involves a combination of assessment procedures. For example, Cooper & Harding (1993), Dunlap, et al (1991), Mace and Lalli (1991), Sasso, et al, (1992), Berg, Wacker & Steege (1995), and Steege & Northup (1998) describe methods of combining indirect, descriptive and functional analysis procedures.

In addition, functional assessment is not limited to the analysis of problem behavior. For example, Daly, Witt, Martens and Dool (1997) described a functional analysis model for evaluating academic performance problems.

Yet another emerging trend in applied behavior analysis is the use of functional communication training. Functional communication training seeks to teach an individual to use appropriate communication to obtain something he or she wants, instead of engaging in problem behavior (Hagopian, L., et al, 1998).

Discrete Trial Training

One of the instructional methodologies frequently used in ABA-based programs is Discrete Trial Training (DTT). Discrete trial training and ABA are not synonymous. While DTT is based upon principles of learning theory and has been demonstrated to be an effective intervention methodology, it represents only one of dozens of teaching strategies within the field of ABA. For example, other methods of teaching used within ABA-based programs include PECS (Picture Exchange Communication System), photo activity schedules, chaining, shaping, graduated guidance, and functional communication training. ABA also relies heavily upon incidental teaching procedures, once children have a core set of skills necessary to learn incidentally. These include attending and imitation.

Discrete Trial Training methodology has been likened to controlling the river of information and interaction which typically confronts the child with autism such that it is presented one drop at a time (Koegel, Russo, Rincover & Schreibman, 1982). This control manages learning opportunities so that skills are more easily mastered by the child. Learning occurs in small steps. Simple skills must be mastered before new learning opportunities are presented, in which the child then builds upon the mastered skill toward a more complex one. Learning opportunities are presented in a “training trial” format.

Each training trial, regardless of the skill objective, consists of four major components:

- 1) The teacher or therapist presents a brief, distinctive instruction or question (stimulus).
- 2) The instruction is followed by a prompt, if the child needs one, to elicit the correct response.
- 3) The child responds correctly or incorrectly (response).
- 4) The teacher or therapist provides an appropriate “consequence.” Correct responses receive a reward, which may be an edible treat, a toy, hugs or praise; incorrect responses are ignored and/or corrected.
- 5) Data are recorded.

Newsom and Rincover (1989) explain discrete trial training can be used to teach basic skills such as attending, as well as very complex verbal and social behaviors necessary to function independently.

Treatment begins with two primary goals: teaching “learning readiness” skills such as sitting in a chair and attending, and decreasing behaviors that interfere with learning, such as noncompliance, tantrums and aggression. In addition, the basic rules of social interaction are established. Children are taught how to learn from the environment through the introduction of clear stimulus-response-reward cycles.

Once the child has learned to sit quietly and attend, more complex skills such as social behaviors and communication can be taught. Social skills training begins with eye contact, and moves toward imitation, observational learning, expressive affection and social play. Communication skills generally begin with receptive object labels, progress to expressive verbal and/or augmentative expressive language, then seek spontaneous communication. As these tasks are mastered, the child is taught to make expressive demands. The goal is that the child will learn that functional language results in something the child wants. Generalization training then moves the drills into more naturalistic environments and incidental teaching (McGee, Krantz & McClannahan, 1985).

Children with autism typically do not learn from their environment spontaneously, and therefore need to be taught virtually everything they are expected to learn (Green, 1995). Therefore, as part of a broader applied behavior analysis intervention, discrete trials target numerous goals and objectives. Consequently an effective ABA intervention requires numerous hours of child:therapist sessions per week. According to Green (1995), “For young children with autism, the treatment of choice is intensive application of the methods of applied behavior analysis. “Intensive” means one-to-one treatment in which carefully planned learning opportunities are provided and reinforced at a high rate by trained therapists and teachers for *at least 30*

(preferably 40) hours a week, 7 days a week, for at least two years. Young autistic children who received less intensive treatment made some modest gains, but normal or near-normal functioning was achieved reliably only when treatment was provided for 30 - 40 hours a week, on average, for at least two years (eg Anderson, et al, 1987; Birnbrauer & Leach, 1993; Fenske, et al, 1987; Lovaas, 1987; Maurice, 1993; McEachin, Smith & Lovaas, 1993; Perry, Cohen & DeCarlo, 1995; Smith, 1993)."

"Lovaas Therapy"

"Lovaas Therapy" derives its name from O. Ivar Lovaas, PhD, a psychologist who has researched methods of applied behavior analysis for over 30 years. Lovaas gained more mainstream recognition from the 1987 publication of a study he conducted with children with autism. Based upon his research, Lovaas concluded intensive behavioral intervention (including the use of discrete trials) offered much hope for improving the outcomes of children with autism. Forty-seven percent of children in the study ultimately gained normal functioning such that they were virtually indistinguishable from their peers (Lovaas, 1987). A follow-up study of these same children in 1993 concluded the results were sustained (McEachin & Lovaas, 1993).

While Lovaas is due credit for the rigor and value of his work, ABA professionals emphasize behavioral intervention in any form is not the domain of any one professional or group. Therefore, "Lovaas Therapy" is an appropriate term only when *specifically* referring to Lovaas' work, methods and protocols. Otherwise, the broader terms "applied behavior analysis" or "ABA" should be used.

Discussion

The effectiveness of ABA-based interventions with persons with autism is well documented, with current research replicating already-proven methods and further developing the field. Documentation of the efficacy of ABA-based interventions with persons with autism emerged in the 1960s, with comprehensive evaluations beginning in the early 1970s.

Hingtgen & Bryson (1972) reviewed over 400 research articles pertinent to the field of autism that were published between 1964 and 1970. They concluded that behaviorally-based interventions demonstrated the most consistent results. In a follow-up study, DeMeyer, Hingtgen & Jackson (1981) reviewed over 1,100 *additional* studies that appeared in the 1970s. They examined studies that included behaviorally-based interventions as well as interventions based upon a wide range of theoretical foundations. Following a comprehensive review of these studies, DeMeyer, Hingtgen & Jackson (1982) concluded ". . .the overwhelming evidence strongly suggest that the treatment of choice for maximal expansion of the autistic child's behavioral repertoire is a systematic behavioral education program, involving as many child contact hours as possible, and using therapists (including parents) who have been trained in the behavioral techniques" (p.435).

Support of the consistent effectiveness and broad-based application of ABA methods with persons with autism is found in hundreds of additional published reports. Baglio, Benavidiz, Compton, et al (1996) reviewed 251 studies from 1980 to 1995 that reported on the efficacy of behaviorally-based interventions with persons with autism. Baglio, et al (1996) concluded that

since 1980, research on behavioral treatment of autistic children has become increasingly sophisticated and encompassing, and that interventions based upon ABA have consistently resulted in positive behavioral outcomes. In their review, categories of target behaviors included aberrant behaviors (ie self injury, aggression), language (ie receptive and expressive skills, augmentative communication), daily living skills (self-care, domestic skills), community living skills (vocational, public transportation and shopping skills), academics (reading, math, spelling, written language), and social skills (reciprocal social interactions, age-appropriate social skills).

In 1987, Lovaas published his report of research conducted with 38 autistic children using methods of applied behavior analysis 40 hours per week. Treatment occurred in the home and school setting. After the first two years, some of the children in the treatment group were able to enter kindergarten with assistance of only 10 hours of discrete trial training per week, and required only minimal assistance while completing first grade. Others, those who did not progress to independent school functioning early in treatment, continued in 40 hours per week of treatment for up to 6 years.

All of the children in the study were re-evaluated between the ages of six and seven by independent evaluators who were blind as to whether the child had been in the treatment or control groups. There were several significant findings:

- 1) In the treatment group, 47% passed "normal" first grade and scored average or above on IQ tests. Of the control groups, only one child had a normal first grade placement and average IQ.
- 2) Eight of the remaining children in the treatment group were successful in a language disordered classroom and scored a mean IQ of 70 (range = 56-95). Of the control groups, 18 students were in a language disordered class (mean IQ = 70).
- 3) Two students in the treatment group were in a class for autistic or retarded children and scored in the profound MR range. By comparison, 21 of the control students were in autistic/MR classes, with a mean IQ of 40.
- 4) In contrast to the treatment group which showed significant gains in tested IQ, the control groups' mean IQ did not improve. The mean post-treatment IQ was 83.3 for the treatment group, while only 53.3 for the control groups.

In 1993, McEachin, et al investigated the nine students who achieved the best outcomes in the 1987 Lovaas study. After a thorough evaluation of adaptive functioning, IQ and personality conducted by professionals blind as to the child's treatment status, evaluators could not distinguish treatment subjects from those who were not.

Subsequent to the work of Lovaas and his associates, a number of investigators have addressed outcomes from intensive intervention programs for children with autism. For example, the May Institute reported outcomes on 14 children with autism who received 15 - 20 hours of discrete trial training (Anderson, et al, 1987). While results were not as striking as those reported by Lovaas, significant gains were reported which exceeded those obtained in more traditional treatment paradigms. Similarly, Sheinkopf and Siegel (1998) have recently reported on interventions based upon discrete trial training which resulted in significant gains in the treated children's IQ, as well as a reduction in the symptoms of autism. It should be noted that subjects in the May and Sheinkopf and Siegel studies were given a far less intense program

than those of the Lovaas study, which may have implications regarding the impact of intensity on the effectiveness of treatment.

Finally, according to a cost/benefit analysis conducted by Jacobson, Mulick & Green (1996), competently-delivered, early, intensive behavioral intervention can offer the hope of unprecedented gains for both children and taxpayers: estimated savings per child to age 22 are about \$200,000; to age 55, \$1,000,000.

Behavioral intervention is not without controversy, despite the empirical support. Detractors theorize behavioral programs produce robotic children. Research reviewed by MADSEC reveals nothing to substantiate this theory. On the contrary, one of the more consistent findings of the research is improved social skills in those children treated (eg Lovaas, 1987; Maurice, 1993). Others question whether Lovaas (1987) used a representative sample of children with autism. While that debate continues, subsequent research using a variety of samples (eg Anderson, et al, 1987; Sheinkopf & Seigel, 1998; Birnbrauer & Leach, 1993; Fenske, et al, 1985) shows that unlike other treatments proposed for autism, there have been no studies which do not support the effectiveness of behavioral intervention. To date, there are no published studies which refute the effectiveness of this approach.

Conclusions

There is a wealth of validated and peer-reviewed studies supporting the efficacy of ABA methods to improve and sustain socially significant behaviors in every domain, in individuals with autism. Importantly, results reported include “meaningful” outcomes such as increased social skills, communication skills academic performance, and overall cognitive functioning. These reflect clinically-significant quality of life improvements. While studies varied as to the magnitude of gains, all have demonstrated long term retention of gains made.

Other major contributions of ABA to the education and treatment of individuals with autism include:

- a large number of empirically-based systematic instruction methods that lead to the acquisition of skills, and to the decrease/elimination of aberrant behaviors;
- a technology for systematically evaluating the efficacy of interventions intended to affect individual learning and behavior; and
- substantial cost/benefit.

Over 30 years of rigorous research and peer review of applied behavior analysis' effectiveness for individuals with autism demonstrate ABA has been objectively substantiated as effective based upon the scope and quality of science. Professionals considering applied behavior analysis should portray the method as objectively substantiated as effective. Methods of applied behavior analysis should be considered to evaluate the effectiveness of any intervention used to help individuals with autism. Researchers should continue to vigorously investigate behavioral intervention as the most promising area of research and treatment benefitting individuals with autism known today. Early interventionists should leverage early autism diagnosis with the proven efficacy of intensive ABA for optimal outcome and long-term cost benefit.

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AUDITORY INTEGRATION TRAINING

Databases Searched	Dates	Search Terms
MEDLINE [®] Advanced	January 1998 - October 1998	'auditory integration and autism'
MEDLINE [®] Advanced	1996 - 1997	
MEDLINE [®] Advanced	1994 - 1995	
MEDLINE [®] Advanced	1992 - 1993	
MEDLINE [®] Advanced	1990 - 1991	
MEDLINE [®] Advanced	1988 - 1989	
PsychINFO	1996 - October 1998	
PsychINFO	1993 - 1995	
PsychINFO	1989 - 1992	

Search Yield: 10 abstracts

Position statement by American Academy of Pediatrics Committee on Children with Disabilities

Original search results available at the MADSEC office upon request.

Notes: Additional information for description and literature review was collected from references within search yield; presentation to the MADSEC Autism Task Force by Janis Ames, MA, CCC-SLP (a Berard Certified AIT Practitioner), and reference to an AIT website.

Description of Auditory Integration Training

Hypersensitive hearing of persons with autism has been widely recognized by many professionals (eg Cordon, 1975; Delacato, 1974; Grandin & Scariano, 1986; Hayes & Gordon, 1977; Rimland, 1964.) Auditory integration training (AIT) was developed in France, by otolaryngologist Guy Berard, on the theory that human behavior is largely conditioned by the manner in which one hears (Berard, 1993).

Auditory integration training is said to address the hearing distortions, hyperacute hearing, and sensory processing anomalies which cause discomfort and confusion in persons suffering from learning disabilities, including autism (Stehli, 1995). Auditory training seeks to retrain the auditory system by correcting hearing distortions. During 20 half-hour training sessions which take place over 10 to 14 days, participants listen with headphones to a musical program modified and filtered through an electronic device called an AudioKinetron (Stehli, 1995).

The cost of this training is currently around \$1250. Practitioners indicate it usually is only

necessary once in a lifetime. Some private insurance companies have paid for auditory integration training.

Discussion

Berard had used auditory integration therapy with over 8,000 individuals with hearing impairments at his clinic in France. Forty-eight of these patients were diagnosed as having autism (Berard, 1993). One patient is reported to have recovered from autism after receiving auditory integration training (Stehli, 1991). Three studies have been conducted to determine the efficacy of this approach in the education and treatment of children with autism (Link, 1997; Rimland & Edelson, 1995; Rimland and Edelson, 1994).

Link (1997) presented case studies of three boys with autism that received 20 half-hour sessions of auditory integration training. The study looked at the impact of AIT on sound hypersensitivity, as well as on cognitive and behavioral problems. Link found no change in hypersensitivity to sound, and few beneficial effects on the behavior or cognitive skills of the three boys.

Rimland and Edelson (1995) conducted an experimental design research study of 18 children, ages 4 to 21 years, using a multiple criteria assessment over a three month period. Assessment tools included the Rimland E-2 Diagnostic Checklist, Aberrant Behavior Checklist (ABC), the Fisher's Auditory Problems Checklist (FAPC), and Hearing Sensitivity Questionnaire. Results indicated a significant decrease in aberrant behaviors of the experimental group, compared to those of the control group (ABC ($p < .01$); FAPC ($p < .05$)). However, these results were not consistently significant in the areas of hypersensitivity to sound or cognitive skills involving comprehension and language (Rimland & Edelson, 1995).

Rimland and Edelson (1995) concluded that the main hypothesis for this research was the premise that hypersensitivity to sound was directly related to aberrant behaviors, cognitive deficits and poor social interaction skills. Therefore the lack of significant data on sound hypersensitivity did not support the use of auditory integration training (Rimland & Edelson, 1995). Howlin (1997) questioned this conclusion, contending that researchers often seek high p values, but that professionals and clinicians are responsible for determining therapeutic value to individual children, and these children did demonstrate some lessened hypersensitivity and a reduction in aberrant behaviors (Howlin, 1997).

Rimland and Edelson (1994) conducted a follow-up study, which surveyed 445 parents of children with autism who had undergone AIT. Results indicated most parents felt auditory integration training was beneficial to their child (Rimland & Edelson, 1994).

Conclusions

There are few validated studies regarding the use of auditory integration training. According to Smith (1996), there is no scientific evidence to substantiate the theory that hypersensitivity to sound causes aberrant behaviors, interferes with social skills, and is a basis for cognitive deficits. In addition, there is currently no scientific evidence to support the effectiveness of auditory integration training in reducing hypersensitivity to sound in children with autism.

According to the American Academy of Pediatrics Committee on Children with Disabilities, current information does not support the use of auditory integration training and, therefore, its use is not yet warranted other than in research protocols.

Preliminary research and anecdotal reports suggest AIT may show promise (Rimland & Edelson, 1994; Rimland & Edelson, 1995; Stehli, 1991; Stehli, 1995), but it is not yet objectively substantiated as effective subject to the rigors of good science. Researchers should consider further investigation using research protocols. Professionals considering AIT should portray the method as experimental, and should disclose this status to key decision makers influencing the child's intervention.

References/Auditory Integration Training

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FACILITATED COMMUNICATION

Databases Searched	Dates	Search Terms
MEDLINE [®] Advanced	January 1998 - October 1998	'autism and facilitated communication', 'facilitated communication,' and 'autism and treatment'
MEDLINE [®] Advanced	1996 - 1997	
MEDLINE [®] Advanced	1994 - 1995	
MEDLINE [®] Advanced	1992 - 1993	
MEDLINE [®] Advanced	1990 - 1991	
MEDLINE [®] Advanced	1989 - 1990	
PsychINFO	1996 - September 1998	
PsychINFO	1993 - 1995	
PsychINFO	1989 - 1992	

Search Yield: 151 publications (studies, articles, reviews); position statements by the American Psychological Association, American Academy of Child and Adolescent Psychiatry, American Speech-Language-Hearing Association, Association for Applied Behavior Analysis, and the American Association on Mental Retardation.

Original search results available at the MADSEC office upon request.

Notes: Additional information for description and literature review was collected from references within search yield; presentation to the MADSEC Autism Task Force by Alan Kurtz, M Ed, Internet sites, and the Center for Community Inclusion.

Description of Facilitated Communication

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. In 1989, Douglas Biklen began to use FC in the United States, with people who have autism.

According to Smith (1996), "Facilitated Communication (Biklen, 1993) 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. To overcome this conjectured problem, trained facilitators (professionals or nonprofessionals who have completed a workshop on the treatment) hold people's hands, wrists, or arms to help them spell messages on a keyboard or a board with printed letters. . . . According to reports, when people who were previously thought to have no communicative language participated in Facilitated

Communication, they began to compose poetry, divulge personal thoughts and feelings, excel at advanced schoolwork, and display many other complex language skills.”

There is some confusion between the terms “facilitated communication” and “augmentative communication” or “augmentative and alternative communication” (AAC). Facilitated communication is based upon the premise that individuals with autism have “undisclosed literacy” (Biklen, 1990). “It is a technique wherein a facilitator touches the hand, arm or shoulder of a person with communication deficits while they jointly point to symbols, letters or words. . . FC is not to be confused with use of appropriately applied manual guidance or other prompts to teach communication and other skills, nor should it be confused with independent use of nonspeech communication systems that may involve letterboards, keyboards, or other symbol systems” (ABA, 1995).

Discussion

Biklen and colleagues have contributed the majority of articles supporting the use of facilitated communication with children with autism. Biklen theorizes people with autism and developmental disabilities are able to display normal to high level intellectual skills, once they are able to communicate through the use of FC. Biklen estimates that 90% of children with autism will be able to communicate using FC (Biklen, 1990, 1992; Biklen & Schubert, 1991; Biklen, et al, 1991; Biklen, et al, 1992; Biklen, 1993). These studies are based on qualitative methodologies and include many anecdotal reports of successful intervention. However, none of these studies were scientifically validated.

Many primary research studies have attempted to replicate the findings of Biklen and his colleagues. According to Eberlin, et al (1993), “To date, all published reports of facilitated communication showing unexpected literacy skills have been based on uncontrolled or poorly controlled case study accounts.” MADSEC’s review of the literature was similarly unable to find any scientific studies which support claims that facilitated communication produces independent communication originating from a person with autism.

Many procedures have been employed to determine the effectiveness of FC. The use of a mechanical tool to support the subject’s arm instead of a facilitator has shown that individuals are unable to independently respond to a statistically significant number of questions without a human facilitator present (Kezuka, 1997). This procedure was not widely tested because proponents of facilitated communication contend the facilitator provides security and trust in the individual’s abilities, and that a bond must be formed prior to communication (eg Biklen, 1990).

Several researchers have used blind testing conditions. In these studies, the facilitators were unaware of the questions presented to the subject, testing information was unknown to the facilitator, or visual stimuli used was undisclosed to the facilitator (eg Bebko, et al, 1996; Braman, et al, 1995; Hirshorn & Gregory, 1995; Simpson & Myles, 1995; Simpson & Myles, 1994, among others.) In each of these studies, subjects were unable to respond correctly to most or all of the questions for which the facilitator lacked information. One controlled study found that out of 720 communicative interactions unknown to a facilitator, subjects were able to disclose correct information during 77 interactions (Sheehan & Matuoizzi, 1996).

Kezuka conducted a study of the ideomotor movements of the facilitator. This was done by analyzing video tape of a facilitated subject one video frame at a time (30 frames per second.) Examination revealed the subject made many quick moves toward various keys, passing the correct keys before returning to them. The subject demonstrated difficulty using a facilitator she had not worked with recently, and was unable to communicate through unknown facilitators. According to the investigators, this study suggests a type of unconscious motor movement by the sender. Numerous visual cues were also noted. Kezuka's findings suggested that the subject received very subtle unconscious cueing from the facilitator, which allowed her to return to the correct key. Kezuka contends the cueing relationship between the facilitator and the subject is merely the result of operant conditioning. Each time the subject responds correctly, the facilitator praises the subject, therefore reinforcing the behavior. The subject becomes very in tune to the motor movements of the facilitator, and is completely dependent upon these to communicate. The facilitator, unaware of these ideomotor movements, is encouraged by the subject's ability to communicate. Kezuka concluded that "The role of contact is not one of emotional support or even simply physical support, but one of motor control." (Kezuka, 1997).

Many professionals urge caution in the use of FC. Moore, et al (1993) says, "The issue of determining the origin of messages in facilitated communication is an important one for several reasons. First, from an ethical standpoint, it is imperative that communications be attributed to the correct source. While this is so for the general population, it is particularly so for people with disabilities who are less able to correct errors of attribution of this sort. Second, an accurate knowledge of a disabled persons' communication skills is necessary if service providers are to make the most suitable programs available to the person. Finally, the nature of the content of some critical communications is such that serious errors of justice may be associated with incorrectly attributed communications."

"Serious errors of justice" may occur because, according to Smith, "one well-known investigator estimated that 25% of typically-developing children are victims of molestation, and that the incidence of molestation in children with autism is "more than four times" [25%]!" (Hence, the "well-known investigator" asserted that more than 100% of children with autism are victims of molestation.) Smith continues, "While such mathematical gaffes are amusing, the real-life effects are not: Accusations of molestation often have arisen from Facilitated Communication, and many of these accusations have been directed at parents. Such accusations almost always prove to be unfounded, as would be expected given the fact that the child did not author them. Even so, some of the accusations have caused children to be taken away from their parents for extended periods of time while investigations were ongoing. Falsely accused families in several countries have spent thousands of dollars defending themselves and have experienced immeasurable trauma" (Smith, 1996).

Bligh and Kupperman conducted a court-requested investigation into the validity of accusations of sexual abuse allegedly made by a 10-year-old girl through facilitated communication. When the evaluation was concluded, lawyers agreed that the communication had been from the facilitator, not the child. It was reported that the child had been removed from her home, and that the child and family suffered much distress and personal anguish (Bligh and Kupperman, 1993). Bligh and Kupperman further raised questions resulting from this case for further consideration:

- “Are school personnel liable for using experimental techniques for which there is no scientific basis when they may result in serious emotional and financial damage to the family?”
- “Are the rights of the child violated by depriving her of an appropriate education because of the use of this technique?” (Bligh and Kupperman, 1993).

At least five respected organizations have issued position papers on facilitated communication. Following are excerpts:

American Psychological Association: “APA adopts the position that facilitated communication is a controversial and unproved communicative procedure with no scientifically demonstrated support for its efficacy” (1994).

American Academy of Child and Adolescent Psychiatry: “FC is not a scientifically valid technique for individuals with autism or mental retardation. In particular, information obtained via FC should not be used to confirm or deny allegations of abuse, or make diagnostic or treatment decisions” (1994).

American Speech-Language-Hearing Association: “Facilitated communication may have negative consequences if it precludes the use of effective and appropriate treatment, supplants other forms of communication, and/or leads to false or unsubstantiated allegations of abuse or mistreatment” (1994).

American Association on Mental Retardation: “The American Association on Mental Retardation does not support the use of this technique [FC] as the basis for making any important decisions relevant to the individual being facilitated without clear, objective evidence as to the authorship of such messages” (1994).

Association for Behavior Analysis: “It is the position of the Association for Behavior Analysis that FC is a discredited technique. Because of the absence of ample objective, scientific evidence that FC is beneficial and that identifies the specific conditions under which it may be used with benefit, its use is unwarranted and unethical” (1995).

Conclusions

Accumulated peer-reviewed, empirically-based research studies have not supported the effectiveness of facilitated communication. Equally important, the research has substantiated the potential for great harm (Foxy, 1995; Margolin, 1994, Myers, 1994). Researchers may consider further investigation using research protocols, with particular care to protect subjects and their families against harm. It is not recommended that professionals consider the use of facilitated communication.

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GREENSPAN'S DIR/"FLOOR TIME"

Databases Searched	Dates	Search Terms
MEDLINE [®] Advanced	January 1998 - October 1998	'autism and Greenspan'
MEDLINE [®] Advanced	1996 - 1997	
MEDLINE [®] Advanced	1994 - 1995	
MEDLINE [®] Advanced	1992 - 1993	
MEDLINE [®] Advanced	1990 - 1991	
MEDLINE [®] Advanced	1989 - 1990	
PsychINFO	1996 - September 1998	
PsychINFO	1993 - 1995	
PsychINFO	1989 - 1992	

Search Yield: 11 abstracts: one relating specifically to children with autism; three summarized articles, which included autism among an array of disabilities.

Original search results available at the MADSEC office upon request.

Notes: Additional information for description and Discussion was collected from publications submitted by MADSEC Autism Task Force members.

Description of Greenspan's DIR/"Floor Time"

Over the past 20 years, Stanley Greenspan, MD and colleagues have published numerous articles on theories of child development. Only one relates specifically to children with autism; others may include references to autism among an array of disabilities. At the National Center for Clinical Infant Programs, Greenspan et al have worked with children with a wide range of disabilities from infancy through age 10. Greenspan and others have created a developmental approach for early intervention with infants and children with disabilities, titled Developmental Individual-Difference, Relationship-Based Model (DIR, commonly referred to as the "Floor Time" approach) (Greenspan, 1998). There have been no peer-reviewed, published studies of Greenspan's DIR/Floor Time's effectiveness for children with autism.

Floor Time is based upon Greenspan's theories of six functional milestones necessary for a child to succeed in further learning and development. According to Greenspan, these are:

- 1) "The dual ability to take an interest in the sights, sounds and sensations of the world and to calm oneself down.
- 2) The ability to engage in relationships with other people.

- 3) The ability to engage in two-way communication with gestures.
- 4) The ability to create complex gestures, to string together a series of actions into an elaborate and deliberate problem-solving experience.
- 5) The ability to create ideas.
- 6) The ability to build bridges between ideas to make them reality-based and logical” (Greenspan, 1998).

DIR/Floor Time includes interactive experiences, which are child directed, in a low stimulus environment, ranging from two to five hours a day. During a preschool program, DIR/Floor Time includes integration with typically-developing peers. Greenspan contends that interactive play, in which the adult follows the child’s lead, will encourage the child to “want” to relate to the outside world. Furthermore, Greenspan stipulates “In this model, the therapeutic program must begin as soon as possible so that the children and their parents are re-engaged in emotional interactions that use their emerging, but not yet fully developing capacities for communication (often initially with gestures rather than words). The longer such children remain uncommunicative and the more parents lose their sense of their child’s relatedness, the more deeply the children tend to withdraw and become perseverative and self-stimulatory” (Greenspan, 1998).

According to Greenspan, intervention must “transform this perseveration into interaction” (Greenspan, 1998). Once this occurs, Greenspan theorizes that the child becomes purposeful, and can imitate gestures, sounds and play (Greenspan, 1998).

Greenspan reports, “We have worked with a number of children diagnosed with autism or PDDNOS between the ages of 18 and 30 months who, now older, are fully communicative (using complex sentences adaptively), creative, warm, loving, and joyful” (Greenspan, 1998).

Discussion

There have been no peer-reviewed, published studies of Greenspan’s DIR/Floor Time’s effectiveness for children with autism.

Conclusions

There have been no peer-reviewed, published studies of Greenspan’s DIR/Floor Time’s effectiveness for children with autism. Researchers should consider investigation using research protocols. Professionals considering Greenspan’s Floor Time should portray the method as without peer-reviewed scientific evaluation, and should disclose this status to key decision makers influencing the child’s intervention.

References/Greenspan’s DIR/Floor Time

Greenspan, S.I. (1998). A developmental approach to problems in relating and communicating in autistic spectrum disorders and related syndromes. *SPOTLIGHT on Topics in Developmental Disabilities*, 1, (4) 1 - 6.

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THE MILLER METHOD

Databases Searched	Dates	Search Terms
MEDLINE [®] Advanced	January 1998 - October 1998	'Miller Method™ and autism'; 'Miller and autism'; 'Miller and Eller-Miller and autism'; 'Language and Cognitive Development Center and autism'.
MEDLINE [®] Advanced	1996 - 1997	
MEDLINE [®] Advanced	1994 - 1995	
MEDLINE [®] Advanced	1992 - 1993	
MEDLINE [®] Advanced	1990 - 1991	
MEDLINE [®] Advanced	1989 - 1990	
PsychINFO	1996 - September 1998	
PsychINFO	1993 - 1995	
PsychINFO	1989 - 1992	

Search Yield: 1 abstract, citing a monograph describing the Language and Cognitive Development Center

Original search results available at the MADSEC office upon request.

Notes: Additional information for description and Discussion was collected from the Miller Method™ website, the Miller Method™ newsletter, a book authored by Dr. Miller, Dr. Miller's presentation to the MADSEC Autism Task Force, and handouts from Dr. Miller distributed at a Miller Method™ conference 12/5/97.

Description of the Miller Method™

In 1965, Arnold Miller, PhD and Eileen Eller-Miller, MA, CCC founded the Language and Cognitive Development Center (LCDC) in Boston, Massachusetts. The LCDC is a Massachusetts Chapter 766-approved day school, serving students with autism/PDD ages 3 - 14. The LCDC specializes in a particular approach to teaching children with autism, the Miller Method™. Additionally, founders of the LCDC have developed their own reading program, the Symbol Accentuation Reading Program.

The LCDC offers professional conferences, training seminars and oversight programs to parents and professionals working with students with autism/PDD.

Professionals at LCDC theorize some children with autism have "system-forming disorders." According to Miller and Eller-Miller (1997), these system-forming disorders impair the child's ability to organize and understand their surroundings, and to become engaged with these surroundings (Miller & Eller-Miller, 1997). Miller and Eller-Miller further theorize that other

children with autism/PDD have “closed system disorders.” Closed system disorders enable the child to interact with the environment, but only in a repetitive and ritualistic manner (Miller & Eller-Miller, 1997). An objective of the Miller Method™ is to expand these systems by keeping the child on task, as well as helping the child to transform stereotypic behaviors into functional interactions.

The Miller Method™ extensively uses adaptive equipment, including platforms (that elevate the child in hopes of increasing eye contact), large swinging balls (to expand the child's reality system), and Swiss cheese boards (to teach motor planning, as well as to increase the child's understanding of his or her relation to environment and space.) (Miller, 1998).

The Miller Method™ Symbol Accentuation Reading Program is designed to teach reading and writing by transforming pictures of objects into words. American Sign Language is used to teach communication (Miller, 1997).

Professionals at the LCDC use an assessment tool designed by the Millers called Umwelt Assessment. According to Miller (1998), the Umwelt Assessment “. . .examines the unique way in which each disordered child experiences reality” (Miller, 1998). From this assessment, an individualized educational plan is developed based upon the child's needs.

Discussion

According to Miller and Eller-Miller (1997), there are five factors which determine how well a child will progress using the Miller Method™. These include:

- Age at which the intervention begins (ideally, before age 3)
- Extent of neurological involvement
- Evidence of a relationship with at least one parent
- Characteristics of system-forming disorders
- Degree of parental support

(Miller & Eller-Miller, 1997)

Miller & Eller-Miller report that of 63 autistic/PDD children who have attended and then left LCDC over 12 years, 48% returned to public schools, and mainstreamed for some or all of their classes; 32% left the Center for other private schools; and 20% were placed in residential placements. (Miller & Eller-Miller, 1998).

Conclusions

Only one study has been conducted to validate overall effectiveness of the Miller Method™. This study was weakly controlled, in that it did not evaluate the direct effects of the intervention, only the post-educational placements of the students.

The single study surveying educational placements of children who leave the Language and Cognitive Development Center is insufficient to validate the program's effectiveness in helping individuals with autism build a wide range of skills, or to further posit theories regarding

outcomes. The Miller Method™ and the theories upon which it is based may have promise, but it is not yet objectively substantiated as effective subject to the rigors of good science. Miller reports that 20% of children leaving the Center are placed in residential programs. Further controlled research comparing this figure with that of residential placement of children emancipating from other forms of intervention would be informative. Researchers should consider further investigation of the Miller Method™, using research protocols. Professionals considering the Miller Method™ should portray the method as experimental, and should disclose this status to key decision makers influencing the child's intervention.

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SENSORY INTEGRATION

Databases Searched	Dates	Search Terms
MEDLINE [®] Advanced	January 1998 - October 1998	'sensory integration and autism'
MEDLINE [®] Advanced	1996 - 1997	
MEDLINE [®] Advanced	1994 - 1995	
MEDLINE [®] Advanced	1992 - 1993	
MEDLINE [®] Advanced	1990 - 1991	
MEDLINE [®] Advanced	1988 - 1989	
PsychINFO	1996 - September 1998	
PsychINFO	1993 - 1995	
PsychINFO	1989 - 1992	

Search Yield: 11 records: two primary research studies (Cook, 1991; Ray, King& Grandin, 1988); one research review (Smith, 1996), and 8 articles.

Original search results available at the MADSEC office upon request.

Notes: Additional information for description and Discussion was collected from references from within search yield; presentation to the MADSEC Autism Task Force by Judy Kimball, PhD, and numerous articles collected randomly.

Description of Sensory Integration

Sensory Integration (SI) therapy is a sensory-motor treatment based upon theories developed over the last 30 years by Dr. A. Jean Ayres. Proponents theorize that sensory integration is an innate neurobiological process (Hatch-Rasmussen, 1995), and that children with autism and other developmental delays experience dysfunction in which sensory input is not integrated or organized appropriately by the brain. Fisher and Murray (1991) describe sensory integration as both "a neurological process, and a theory of the relationship between the neurological process and behavior."

According to Fisher, Murray and Bundy (1991) there are five major assumptions upon which SI theory is based. These are:

- 1) ". . . there is plasticity within the central nervous system. Plasticity refers to the ability of the brain structure to change or be modified. . .
- 2) . . . the sensory integrative process occurs in a developmental sequence. In normal development, increasingly complex behaviors develop as a result of the circular process,

and behaviors present at each stage in the sequence provide, in turn, the basis for the development of more complex behaviors. . .

- 3) . . . the brain functions as an integrated whole, but is comprised of systems that are hierarchically organized. . .
- 4) . . . evincing an adaptive behavior promotes sensory integration, and, in turn, the ability to produce an adaptive behavior reflects sensory integration. . .
- 5) . . . people have an inner drive to develop sensory integration through participation in sensorimotor activities. . .”

(Fisher, Murray & Bundy, 1991)

Sensory integrationists theorize sensory dysfunction is rooted in the central nervous system, and that successful integration of sensory input requires treatment. This treatment is comprised of vestibular, proprioceptive, and/or tactile stimulation.

Ayres (1979) describes sensory integration therapy as sensory stimulation and subsequent adaptive responses which evolve according to the child's neurological needs. Therapy techniques include vestibular stimulation such as swinging in a hammock, and tactile stimulation achieved by brushing parts of the child's body (Smith, 1996). SI therapy is viewed as a direct intervention that can improve nervous system function. This is done by providing the child with enhanced levels of sensory information gleaned during physical activities that are meaningful to the child, and that elicit adaptive behaviors (Koomar & Bundy, 1991).

SI theorists also postulate that children with sensory dysfunction are either over- or under-responsive to sensory input. Children with autism may be startled by a slight sound (hypersensitivity), or may totally tune out external stimuli, such as language (under-responsive). SI practitioners further postulate that self-stimulation and stereotypic activities characteristic of many autistic children may be related to sensory dysfunction, and that therefore SI therapy may reduce the rates of self-stimulation and self-injurious behaviors.

According to a critique by Arendt (1988), SI therapy does not seek to teach higher order skills, but rather to rearrange brain functioning (sensory processing capability) as a precursor to learning. Arendt challenges basic SI theory in his critique; he also asserts that even if Ayres' theories of nervous system hierarchy and neural plasticity are valid, the SI treatment model does not inherently address them. (Arendt, 1988).

It is important to note that while sensory integration may be practiced by occupational and physical therapists, SI does not constitute the full and exclusive range of methods used by OTs and PTs to achieve fine motor, gross motor and adaptive daily living skills. Other methods used in OT and PT include physical prompting, shaping, and modeling, among others.

Discussion

Ray, King and Grandin (1998) examined the effect of vestibular stimulation (swinging) on speech sounds in children with autism. The researchers found a 15% increase in vocalizations while the child was on a swing than in the absence of this vestibular stimulation.

Cook (1991) presents anecdotal case studies of on-task behavior and attending skills in three children with autism who received sensory motor interventions. Cook reported both teachers and parents noted significant improvements in both domains, and in all three children. However, these reports are based upon parent and teacher impressions, not empirical data, and therefore could be vulnerable to reporter bias and failure to establish SI as an independent variable responsible for the reported improvement.

According to Murray and Anzalone (1991), "care is required not to overstep the boundaries of sensory integration theory when applying these procedures to children and adults with autism." In a study designed to test the effectiveness of SI on self-injurious behaviors (SIB), Mason and Iwata (1990) found that SI was less effective than behavioral treatment in reducing SIB; in one case, the rate of SIB actually increased with SI treatment. A review of the literature did not yield any study concluding SI is an effective treatment for SIB or self-stimulation.

Arendt (1988) examined the effectiveness of SI therapy as it applied to individuals with mental retardation. Arendt found that the database of studies was small, and that the methodology in most of the studies under his consideration had serious flaws. These flaws included examiner bias and uncontrolled variables.

Ottenbacher's analysis concluded that SI had a positive effect on the subjects receiving the therapy (1982). However, he later reports that his study had several limitations associated with interpretation of the data (1991): there was no consistency in subjects' areas of improvement, and much of the sub-analysis was confounded. Ottenbacher concludes in a 1991 textbook on sensory integration that "previous attempts to synthesize and interpret existing sensory integration research reveal that a clear empirical consensus does not exist regarding the validity of sensory integration theory, or the effectiveness of sensory integration practice." Ottenbacher further concludes more research is needed to reach empirical consensus.

Smith examined several investigations evaluating SI's effectiveness for children with developmental disabilities (Smith, 1996). Smith concludes SI did not decrease self injury, did not reduce ritualistic behaviors and did not show increases in motor development. Like Arendt, Smith concludes "studies on sensory integration therapy are sparse, but they have consistently yielded adverse findings" (Smith, 1996).

Conclusions

Current research does not support SI as an effective treatment for children with autism, developmental delays or mental retardation; nor has the limited research to date been able to identify SI as an independent variable responsible for positive change in a child's behaviors or skills. In at least one study, SI was shown to actually increase self-injurious behaviors.

According to Smith, "Though Sensory Integration Therapy does not appear to enhance language, control disruptive behaviors, or otherwise reduce autistic behaviors, it may offer enjoyable, healthy physical activity (1996)."

Anecdotal reports suggest SI may show promise, but it is not yet objectively substantiated as effective for children with autism subject to the rigors of good science. Research is currently in process at the Denver Children's Hospital that may further validate or invalidate SI theory and effectiveness. More researchers should consider further investigation using research protocols. Professionals considering SI should distinguish the intervention from other methods that may be employed by occupational and physical therapists to achieve fine motor, gross motor and adaptive daily living goals. Professionals considering SI interventions should also portray the intervention as experimental, and disclose this status to key decision makers influencing the child's intervention.

References/Sensory Integration

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THE SON-RISE PROGRAM

Databases Searched	Dates	Search Terms
MEDLINE [®] Advanced	January 1998 - October 1998	'Son-Rise and autism'; 'Option and autism'.
MEDLINE [®] Advanced	1996 - 1997	
MEDLINE [®] Advanced	1994 - 1995	
MEDLINE [®] Advanced	1992 - 1993	
MEDLINE [®] Advanced	1990 - 1991	
MEDLINE [®] Advanced	1989 - 1990	
PsychINFO	1996 - September 1998	
PsychINFO	1993 - 1995	
PsychINFO	1989 - 1992	

Search Yield: 0 published articles; one book, *Son-Rise: the Miracle Continues*.

Original search results available at the MADSEC office upon request.

Notes: Additional information for description and Discussion was collected from the world wide web, and a catalog of the Option Institute.

Description of the Son-Rise

The Son-Rise Program for Families with Children with Special Needs is a program offered at the Options Institute. The Options Institute is an educational organization founded in 1983 by Barry Neil Kaufman and Samahria Lyte Kaufman.

The Option Institute teaches the Option Process[®]. This process involves a loving and non-judgmental method for resolving unhappiness and discarding self-limiting beliefs (The Option Institute and Fellowship, 1997). The Option Institute teaches a variety of programs and seminars for people of all ages.

The Son-Rise Program was created by Barry and Samahria Lyte Kaufman in the 1970s, as a means to teach their own son, who was diagnosed with autism and mental retardation. The program ranges from one week to six months, and is designed to teach parents, professionals and support staff of children with a wide range of disabilities how to implement home-based programs based upon the Kaufmans' theories of learning.

Son-Rise Programs include a start-up program, intensive program and advanced training program. The start-up program is a five-day group seminar that provides basic components of a

home-based program. The intensive program is a one week seminar providing 40 hours of one-on-one work with a trained facilitator and the child. The advanced training seminar is a follow up program after the implementation of a home-based program (The Option Institute and Fellowship, 1997).

According to Levy (1998), the Son-Rise Program does not guarantee results. The approach is based upon “. . .becoming a student of the child’s world, observing, learning, assisting and supporting the child’s flowering in a loving and non-judgmental environment” (Levy, 1998).

The Son-Rise Program does not seek to provide the child with information, or to teach the child to master predetermined skills. Instead, the program views the child’s current level of performance as being the best that the child can do; if the child could do better, he would (eg, if the child could follow instructions, he would). The Son-Rise program emphasizes total acceptance of the child, and encourages him to become a more motivated and participating individual (Levy, 1998).

Discussion

There have been no peer-reviewed, published studies of The Son-Rise Program’s effectiveness or outcome statistics.

Son Rise: The Miracle Continues chronicles the experiences of Barry and Samahria Lyte Kaufman as they created a program to meet the needs of their young son, diagnosed with autism and an IQ under 30. According the Kaufman (1997), their son currently has a near genius IQ, and no traces of his original condition.

Conclusions

There have been no studies of the Son-Rise Program’s effectiveness. Researchers should consider investigation using research protocols. Professionals considering Son-Rise should portray the method as without scientific evaluation of any kind, and should disclose this status to key decision makers influencing the child’s intervention.

References/Son-Rise

Levy, J. (1998). The autism treatment center of America. The Son-Rise Program for families with special children (America On-Line) www.options.org. Available: Internet.

The Option Institute and Fellowship (1997). *The Option Institute: The worldwide teaching center for the Option Process. 1998 programs catalog.*

TEACCH

Databases Searched	Dates	Search Terms
MEDLINE [®] Advanced	January 1998 - October 1998	'TEACCH and autism'
MEDLINE [®] Advanced	1996 - 1997	
MEDLINE [®] Advanced	1994 - 1995	
MEDLINE [®] Advanced	1992 - 1993	
MEDLINE [®] Advanced	1990 - 1991	
MEDLINE [®] Advanced	1988 - 1989	
PsychINFO	1996 - September 1998	
PsychINFO	1993 - 1995	
PsychINFO	1989 - 1992	

Search Yield: 36 abstracts from books and journals, and a World Wide Web page, which contained basic information and additional bibliographic citations about TEACCH.

Original search results available at the MADSEC office upon request.

Notes: Additional information for description and Discussion was collected from the University of Maine Systems library catalogs, and the World Wide Web for related books, documents and presentations.

Description of TEACCH

TEACCH (Treatment and Education of Autistic and Communication Handicapped Children) is a statewide program in North Carolina.

According to Trehin, "TEACCH is not a single approach and even less a method. It is a state program that tries to respond to the needs of autistic people using the best available approaches and methods." (Trehin, 1998). It is a program of services which makes use of several techniques, of several methods, in various combinations, depending upon the individual person's unique needs and emerging capabilities."

In a 1988 article, Director of Division TEACCH Dr. Gary Mesibov addressed misunderstandings about the TEACCH program and philosophy while emphasizing its values and purpose:

"Developed in the early 1970s by our founder, Eric Schopler, the TEACCH approach includes a focus on the person with autism and development of a program around this person's skills, interests and needs. The major priorities include centering on the individual, understanding

autism, adopting appropriate adaptations, and a broadly based intervention strategy building on existing skills and interests.”

“Structured teaching is an important priority because of the TEACCH research and experience that structure fits the “culture of autism” more effectively than any other techniques we have observed. Organizing the physical environment, developing schedules and work systems, making expectations clear and explicit, and visual materials have been effective ways of developing skills and allowing people with autism to use these skills independently of direct adult prompting and cueing. Structured teaching says nothing about where people with autism should educate; this is a decision based on the skills and needs of each individual student. Some can work effectively and benefit from regular education programs, while others will need special classrooms for part of all of the day where the physical environment, curriculum, and personnel can be organized and manipulated to reflect individual needs. Division TEACCH believes that the interests of people with autism are best served with coordinated and cooperative programming based on consistent principles over a lifetime.” (Mesibov, 1998).

The TEACCH mission is:

- To enable individuals with autism to function as meaningfully and as independently as possible in the community;
- To provide exemplary services to individuals with autism and their families, and those who serve and support them;
- As a member of the University community, to generate knowledge; to integrate clinical services with relevant theory, practice, and research on autism through training and publications locally, nationally and internationally.

Visual cues for instruction and prediction assist students in gaining independence (Trehin, 1998). Psycho educational therapists and teachers keep detailed notes and data on each session with a student (Lord & Schopler, 1994), as documentation of outcome data of students involved with the TEACCH program. Schopler, Mesibov and their staff also utilize components of behavioral approaches in teaching self-care skills and managing aberrant behaviors.

Additionally, TEACCH professionals draw upon concepts of sensory integration therapy in determining causation of aberrant behaviors or lack of skill acquisition. For example, professionals at Division TEACCH theorize pain is at the root of many aberrant behaviors. If a child is over-stimulated in an environment, the child may be in physical pain and emit aberrant behaviors. A behavioral plan for this child would involve removing the child from the environment. (Trehin, 1998).

According to Trehin, management of self-injurious or violent behavior surpasses what can be expected through regular intervention. These behaviors require specialists and non-aversive behavior modification techniques (Trehin, 1998).

Proponents of the TEACCH model do not claim to “cure” autism. Instead, a main goal of the program is to help children maximize their autonomy through increased communication skills, social awareness and independent decision-making skills.

“Project TEACCH is aimed primarily at designing sheltered settings that help children make use of the skills they already possess, rather than at helping children to enter more “normal” or “typical” settings (C. Lord & Schopler, 1994)” (Smith, 1996).

Discussion

According to Schopler, over 250 research studies were conducted by or in collaboration with Division TEACCH between 1964 and 1990 (Schopler, 1991). Summaries of these studies are available at the Department of Psychiatry in the University of North Carolina School of Medicine at Chapel Hill.

Schopler, Mesibov and Baker (1982) evaluated the outcomes of 647 students emancipated from or presently enrolled in the TEACCH program, ranging in age from 2 to 26 years of age. Fifty-one percent of these students have a diagnosis of autism. One group of students received only a diagnostic evaluation; one group received an evaluation and parent training; and a third group received an evaluation and placement in the TEACCH classroom. Questionnaires were mailed to participants’ homes to be filled out by parents of participating students. Results indicated that persons most involved in the program saw the most improvements. Additionally, adults and adolescents in the study were found to have an institutionalization rate of only 7%. This was compared to the rate of institutionalization of adolescents and adults with autism prior to the introduction of Division TEACCH in the 1960s of 39% to 74% (Schopler, Mesibov & Baker, 1982).

Ozonoff and Cathcart (1998) conducted a study of the effectiveness of a TEACCH home-based program. In the program, parents were taught how to work with their preschool child with autism in the home setting. Two groups of 11 children were matched by age, diagnosis, and severity of autism characteristics.

The control group received no programming, and the treatment group received four months of home-based intervention. Each group was given a pre- and post-test. Results indicate that children in the treatment group made significant progress and demonstrated overall improvement that was three to four times greater than that of the control group (Ozonoff & Cathcart, 1998).

Three additional follow-up studies have been conducted to document outcome data of students who received TEACCH services (Lord, 1991; Venter, Lord & Schopler, 1992; and Lord & Schopler, 1998). These studies have indicated substantial increases in IQ scores. Children that received services beginning at the age of three, who were non-verbal and had IQ scores ranging from 30 - 50, demonstrated a 22 to 24 point increase in IQ scores by the age of seven (Lord & Schopler, 1989). In each of these studies, gains were most significant in very young children who were non-verbal prior to intervention (Lord & Schopler, 1994).

Conclusions

According to Schopler (1991), over 250 research studies have been conducted by or in collaboration with Division TEACCH since 1965. These have related to the nature of autism, structured teaching, working with families, assessment, language and communication, independence, vocational skills, social and leisure skills, and behavior management.

However, this extensive research includes few peer-reviewed studies of outcome replications conducted by researchers not affiliated with TEACCH. Dr. Gary Mesibov concedes the difficulty in objectively substantiating the effectiveness of TEACCH based upon the scope and quality of scientific research:

“Demonstrating the effectiveness of a large and complex program such as Division TEACCH is difficult. The problem is compounded by the organic basis of autism, and the focus of Division TEACCH on lifelong adaptation, which do not lend themselves to superficial cures or clearly defined milestones” (Mesibov, 1997).

Research conducted by TEACCH and anecdotal reports suggest TEACCH shows promise (Lord, 1991; Lord & Schopler, 1989; Lord & Schopler, 1994), but it is not objectively substantiated as effective by independent researchers. Independent researchers should consider further investigation using research protocols. Professionals considering TEACCH methods should portray the program as lacking independent verification of its effectiveness, and should disclose this status to key decision makers influencing the child's intervention.

References/TEACCH

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SUMMARY CONCLUSIONS, IMPLICATIONS AND RECOMMENDATIONS

Summary Conclusions

Between 1991 and 1998, the number of Maine children classified by educators as having autism has increased from 42 to 304. This number is likely conservative: many children meeting the diagnostic criteria for autism may be classified as having speech/language disorder, behavior impairment, and/or as being multi handicapped. Educators and other interventionists must be adequately informed to:

- ensure services to children with autism are effective
- reduce litigation
- invest limited financial and practitioner resources wisely
- advocate for sufficient federal, state and local funding to meet service needs, and
- develop the professional human resource base necessary to meet service needs.

The importance of early, intensive intervention for children with autism cannot be overstated. Numerous studies have concluded outcomes are substantially more positive when the children begin receiving effective, intensive intervention as early as possible in life (including the potential to recover normal functioning such that an autistic child may become virtually indistinguishable from his peers) (eg Fenske, et al, 1985; Lovaas, 1987; Maurice, 1993; Perry, Cohen & DeCarlo, 1995). Furthermore, early, intensive, effective intervention offers the hope of significant cost/benefit (Jacobson, Mulick & Green, 1996).

Based upon a thorough examination of numerous methodologies considered as interventions for children with autism, the MADSEC Autism Task Force has characterized the interventions reviewed as follows:

- **Substantiated as effective, based upon the scope and quality of research:**
Applied behavior analysis. In addition, applied behavior analysis' evaluative procedures are effective not only with behaviorally-based interventions, but also for the systematic evaluation of the efficacy of *any* intervention intended to affect individual learning and behavior. ABA's emphasis on functional assessment and positive behavioral support will help meet heightened standards of IDEA '97. Its emphasis on measurable goals and reliable data collection will substantiate the child's progress in the event of due process.
- **Shows promise, but is not yet objectively substantiated as effective for individuals with autism using controlled studies and subject to the rigors of good science:**
Auditory Integration Training, The Miller Method™, Sensory Integration, and TEACCH.
- **Repeatedly subjected to the rigors of science, which leads numerous researchers to conclude the intervention is not effective, may be harmful, or may lead to unintended consequences:**
Facilitated Communication.
- **Not scientifically evaluated:**

Greenspan's DIR/"Floor Time," Son-Rise.

Implications

It is neither the mission nor the intent of the MADSEC Autism Task Force to propose public policy regarding effective interventions for children with autism. Rather, the Task Force seeks to provide detailed information to help families, educators and other service providers make informed decisions.

The thoughtful analysis offered in this document may provoke increased demand for certain autism interventions, such as applied behavior analysis. Child Development Services may also experience added pressure for early identification of children with autism, as well as immediate, intensive, effective intervention.

Practitioners of applied behavior analysis require specialized training beyond that normally gained by professionals specializing in behavior impairment, special education or psychology. Increased demand for applied behavior analysis will precipitate the need for professional development resources to ensure ABA practitioners have sufficient and appropriate training.

Recommendations

- 1) Develop an aggressive plan to encourage screening of every child for autism as part of routine pediatric care.
- 2) Improve data collection systems to more accurately determine the number of Maine children who meet the diagnostic criteria for autism, independent of or in addition to other impairments.
- 3) Justify and seek additional funding from the Maine State Legislature for increased early autism identification and intervention.
- 4) Ensure services for children with autism are based upon scientifically validated procedures.
- 5) Ensure that services to children with autism include systematic instruction procedures focusing on both the acquisition of skills and the decrease/elimination of interfering behaviors.
- 6) Require ongoing evaluation of autism interventions using controlled studies and subject to the rigors of good science. Ongoing evaluation should minimally include a credible method of evaluation, and criteria for determining whether to terminate or continue the intervention.
- 7) Identify and recruit qualified behavior analysts from within and outside of Maine as required to meet current service needs.
- 8) Convene a Task Force charged with developing resources sufficient to meet and support the demand for applied behavior analysis.

ABOUT THE TASK FORCE MEMBERS

Christine Bartlett earned her M Ed specializing in Early Childhood Special Education from Loyola University in Chicago. Ms. Bartlett is a consultant in special education to the Maine Department of Education. In that capacity as well as independently, she serves on committees including the Council for Exceptional Children, Council for Children with Behavior Disorders, International Correctional Education Association, Special Education Interest Group, Juvenile Justice Interest Group, MPL Chapter 790 Oversight Committee, Maine's Department of Mental Health, Mental Retardation and Substance Abuse Service's Task Force on Autism, Mental Retardation and Developmental Disabilities, Children's Policy Committee, Pooled Flexible Funding Steering Committee, and the MADSEC Professional Development Committee.

Michael Butler received his MS in Exceptionality from the University of Southern Maine, and will complete work in USM's School Psychology master's program in 1999. Currently Mr. Butler is Director of Special Education for MSAD #58. He has also been Special Education Director for MSAD #74, and served in special education resource/composite rooms earlier in his career. Along with Shirley Tawney, Mr. Butler is co-chair of MADSEC's Autism Task Force.

Bruce Chesley has been Executive Director of the Autism Society of Maine for three years. He has presented numerous workshops on autism across the state. Mr. Chesley serves on the advisory committee of the Maine Department of Education's Comprehensive System of Personnel Development group. In addition, he works with families and school systems to ensure proper placement and educational programming for students with autism.

Lew Collins received his BA in Psychology from Northern Arizona University, and will complete his MS Ed in Educational Leadership-Special Education Administration at the University of Southern Maine in May, 1999. His career in education includes a tenure as an alternative education guidance counselor for at-risk and incarcerated adolescents. Mr. Collins currently serves as Program Director for Child Development Services/Franklin County, a position he has held since 1986.

Stephanie Cote-Zashut earned her BS in Elementary Education and Special Education from Northeastern University. Ms. Cote-Zashut has taught children with autism in center- and home-based settings, and is currently a Child and Family Specialist for Child Development Services/SEARCH.

Jane Palmer received her BS in Child Development and MS in Special Needs from the University of Maine at Orono. Ms. Palmer has taught for 25 years. She is currently a special education teacher with SAD 48. Two of her students have autism.

Lora Perry received her MS in Business Education from New Hampshire College. She and her husband Steve are the parents of five-year-old twin boys with autism. The twins have been in an intensive home-based program for two years. Prior to resigning to devote herself to her sons' care, Ms. Perry developed and managed computer literacy education for 2500 clinical and administrative staff at Maine Medical Center. Ms. Perry has become a passionate advocate for early autism diagnosis and effective, scientifically validated treatment for all individuals with special needs. She currently serves with Maine Public Law Chapter 790 working groups,

Maine's Managed Care Steering Committee, and Maine's Department of Mental Health, Mental Retardation and Substance Abuse Services' Task Force on Autism, Mental Retardation and Developmental Disabilities. Ms. Perry is a Board member of the Association for Science in Autism Treatment (ASAT), and Child Development Services/SEARCH.

Tim Rogers received his PhD in Clinical Psychology from the University of Georgia, and completed his clinical internship at Medical University of South Carolina. Dr. Rogers moved to Maine in 1986 to accept a position as Director of Behavioral and Developmental Pediatrics at Eastern Maine Medical Center, and has been in private practice since 1991. Dr. Rogers currently provides behavioral intervention consultation to more than fifteen school districts, CDS sites and Maine's Department of Mental Health, Mental Retardation and Substance Abuse Services, to meet the needs of children with autism, developmental or learning disorders, and behavioral impairments.

Ann Schoenthaler-Ervin is a Licensed Psychologist and Certified School Psychological Services Provider practicing in Waterville. Dr. Schoenthaler-Ervin completed her doctoral studies at the University of Connecticut and her clinical internship at Kennebec Valley Mental Health Center. Currently, she consults to a variety of schools statewide, and is a member of the clinical/medical staff at MaineGeneral Medical Center. Dr. Schoenthaler-Ervin is also currently chair of the Maine Psychological Association, Division of Child, Adolescent and School Psychology.

Murray Shulman received his doctorate in Educational Administration, following undergraduate and master's degree studies in Special Education and Philosophy, all at the University of Maine at Orono. Dr. Shulman has been a special education teacher and administrator for 25 years. He is currently Director of Pupil Services for the Bangor School Department, a position he has held for ten years. Dr. Shulman also serves as chairman of the Regional Advisory Board/Southern Penobscot Regional Program for Children with Exceptionalities.

Colette Sparks received her M Ed from Westfield State College/Massachusetts. She has continued her studies to help children with autism by attending workshops exploring a variety of topics. Ms. Sparks serves on the Alternative Assessment Committee, ADA Transition Team, and the Special Education Team in Brunswick, as well as serving as a mentor teacher. Currently Ms. Sparks is an Elementary Functional Skills teacher at the Coffin School in Brunswick.

Mark Steege received his PhD in School Psychology from The University of Iowa, after undergraduate and master's studies at Iowa State University and University of Iowa, in Psychology and School Psychology. Dr. Steege is a Licensed Psychologist, Certified School Psychological Services Provider, and a Nationally Certified School Psychologist. He is a member of the Association for Applied Behavior Analysis, and the National Association of School Psychologists. He is on the Editorial Boards of the *Journal of Applied Behavior Analysis* and *Proven Practice*, and a member of the Professional Advisory Board of New England Center for Children. Dr. Steege currently is Associate Professor of School Psychology at the University of Southern Maine. He has published numerous studies, articles and book chapters focusing on individuals with autism.

Christine Szewczyk received her BA in Communications from St. Mary's College in Indiana. She and her husband David have three children, including a six-year-old girl with autism, who has been in an intensive home- and school-based intervention program for three years. Ms. Szewczyk has been a school volunteer, and a therapist for children with autism. She currently serves on the Board of the Center for Communication and Learning.

Shirley Tawney earned an MS degree in Education from University of Kansas, and one from University of Vermont in Special Education, under UV's "Consulting Teacher Program." Ms. Tawney's career includes teaching in Kansas, Germany, Japan, and the Philippines. She has been Director of Special Education in Bath since 1988, after tenures as Special Education Director in Bangor and Bennington, VT. Along with Mike Butler, Ms. Tawney is co-chair of the MADSEC Autism Task Force.

SPECIAL THANKS TO:

Kathryn Tyrrell earned her BS degree in Human Development from Wheelock College in Boston, Massachusetts. She completed her MS in Special Education at the University of Southern Maine in 1999. Her studies at USM have concentrated on the education of children with autism. Ms. Tyrrell currently teaches children with autism, and consults to public schools serving the needs of students with autism. Ms. Tyrrell served as research assistant to the MADSEC Autism Task Force.

Marilyn White describes herself first and foremost as a parent and homemaker. In addition, she serves as secretary to the MADSEC Autism Task Force, and as part-time support staff to the MADSEC office. Ms. White has been a substitute teacher in local schools for 25 years, a census worker, and an adventurous traveler.

Penelope Morrell has been the MADSEC Administrative Assistant/Office Manager for three years. She has completed numerous computer software courses, including Designing a Web Page Using HTML. Ms. Morrell's responsibilities include assisting the MADSEC Executive Director, accounting, and managing the office. Ms. Morrell also serves as Administrative Assistant to the Board of Appeals in Belgrade, where she and her husband of 30 years reside.

Appendix A

Biobehavioral Units (BBUs)

Some children with autism have complex biobehavioral issues including seizure activity, self injury, tantrums, aggression, and property destruction. Combined with severe deficits in functional communication, these behaviors may require inpatient assessment. Currently only four BBUs of varying size and service exist in the United States:

Children's Seashore House
3405 Civic Center Boulevard
Philadelphia, PA 19104-4388
(215) 895 - 3744

Kennedy Krieger Institute
707 North Broadway
Baltimore, MD 21205
(410) 502 - 9400, or (888) 554 - 2080
fax (410) 502 - 8951
www.kennedykrieger.org

The University of Iowa
Biobehavioral Unit
Division of Developmental Disabilities
Department of Pediatrics
251 University Hospital School
Iowa City, IA 52242
(319) 353 - 6450

Western Psychiatric Institute
University of Pittsburgh
3811 O'Hara Street
Pittsburgh, PA 15213
(412) 624 - 2100

Of these, Children's Seashore House and Kennedy Krieger are widely acknowledged as offering the most comprehensive services.

Developmental Evaluation Clinics (DECs)

There are five DECs in Maine:

Cary Medical Center
163 Van Buren Road, Suite 1
Caribou, ME 04736
(207) 498 - 3111

Child Health Center
625 Court Street
Auburn, ME 04210
(207) 782 - 5437
fax (207) 753 - 0105

Eastern Maine Medical Center
417 State Street, Suite 310
Bangor, ME 04402 - 0404
(207) 973 - 7679

Edmund N. Ervin Pediatric Center
MaineGeneral Medical Center
Seton Unit
30 Chase Avenue
Waterville, ME 04901
(207) 872 - 4286
fax (207) 872 - 4060

Spurwink Clinic
17 Bishop Street
Portland, ME 04103
(207) 871 - 1235

Information Exchange

Maine State Library
Station 64
Augusta, ME 04333
1 - 800 - 322 - 8899
(207) 287 - 5620
fax (207) 287 - 5624

Organizations

Association for Behavior Analysis
213 West Hall
Western Michigan University
1201 Oliver Street
Kalamazoo, MI 49008 - 5052
(616) 387 - 8341; (616) 387 - 8342
fax (616) 387 - 8354

Association for Science in Autism Treatment
(ASAT)
175 Great Neck Road, Suite 406
Great Neck, NY 10021
(516) 466 - 4400
fax (516) 466 - 4484
ASAT@autism-treatment.org

Autism Society of Maine
PO Box 597
Gardiner, ME 04345
(207) 582 - 7727 or (800) 273 - 5200
fax (207) 582 - 3638

Families for Early Autism Treatment (FEAT)
PO Box 255722
Sacramento, CA 95865-5722
(916) 843-1536

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

Screening Children for Autism

CHAT
The British Journal of Psychiatry, (1996), 168, 158 - 163; The British Journal of Psychiatry,
(1992), 161, 839 - 843.

(CHAT can be obtained from FEAT: See above for address and phone number.)

CARS
Schopler, E., Reichler, R. J., & Rochen-Renner, B. (1988). Childhood Autism Rating Scale,
Western Psychological Services.

Appendix B

MADSEC recommends readers review the following:

Green, G. (1996). Evaluating claims about treatment for autism. In C. Maurice, G. Green & S. Luce (Eds.), *Behavioral Intervention for Young Children with Autism* (pp 15 - 28). Austin, TX: Pro-Ed.