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Memorandum

To: Ruby Shamir
From: Evelyn F. Shaw
Date: 08/03/99
Re: OSEP and other National Efforts on Behalf of Children with Autism
Spectrum Disorders and Their Families

Enclosed you will find the following information:

- National Institute of Child Health and Development Collaborative Programs of Excellence in Autism (CPEAs) with contact information for Dr. Marie Bristol-Power.
- OSEP funded National Academy of Science project with contact information for Jim McGee, Study Director.
- OSEP funded Institutes of Higher Education Projects (young children with autism)
- NECTAS Resource Collection on Autism Spectrum Disorders (Kathy Whaley and Evelyn Shaw, editors) including Overview, Considerations for Intervention and Education, Legal Issues Under IDEA, Glossary of Terms, National Contacts and Other References on ASD in Early Childhood, OSEP-Funded Early Childhood Projects and Project Materials on ASD, Annotated Bibliography on ASD
- Contact information for Carie Rothenbacher, Instructional Systems Specialist, Special Education, Department of Defense Education Activity (DODEA), 4040 North Fairfax Drive, Arlington, VA 22203 (703-696-4492, ext. 1951).
NECTAS will be facilitating a 3-day, action-planning summit in early August to help the Department of Defense develop their system capacity to serve young children with autism. You may wish to contact her about DODEA's funding for this population.

Child Health Institute Launches International Network of Collaborative Programs of Excellence in Autism (CPEAs)

Dr. Duane Alexander, Director of the National Institute of Child Health and Development (NICHD), says that autism is an important child health problem and should be solved like we solve other biological problems in children. He announced the June 1, 1997, start of a five-year, \$27 million, international network of 10 Collaborative Programs of Excellence in Autism (CPEA) to unravel the mysteries of this developmental disorder that probably begins some time early in brain development. Dr. Alexander noted, "This is the largest commitment to a single autism research venture in history. This neuroscience network will include more than 1000 families and joins scientists at 25 universities throughout the US and in four foreign countries (Canada, Britain, France, and Germany) in learning about causes, including genetics; brain structure and function; and how autism changes over the lifespan." The Network is co-funded by the National Institute of Deafness and Other Communication Disorders (NIDCD), and the NIH Office of Alternative Medicine (OAM).

The CPEAs have brought together premier researchers in autism and outstanding scientists who have never before worked in autism, with high tech tools to find out how autism develops. This group of scientists includes those who have done some of the most outstanding research on diagnosis, brain development, communication and social development; scientists who have succeeded in discovering the genes for other disorders such as Alzheimer's and Duchenne's Muscular Dystrophy; worldclass brain imaging teams; and scientists who are studying children as early as one year of age to see what behaviors should give us our first clues so intervention can begin as soon as possible.

Your Help is Critical

"This is an extraordinary example of scientists working together. Now help from families is critical if this Network is going to succeed in making a breakthrough in autism", said Dr. Bristol, CPEA Network Coordinator. Volunteers are particularly needed for the studies of families with more than one child with an autism disorder. Below is a list of the locations for the ten different Collaborative Programs of

Excellence in Autism (CPEAs), a brief description of the research focus for each, and information about whom to contact if your family wants to participate in the study. Each of the ten CPEAs is focusing on some unique aspects of autism, but all will study the causes of autism, brain development, and behavior in autism. They will all use a common diagnostic system, family history, and shared aspects of procedures and protocols. Some common measures will also be used across all projects to allow for rapid replication of findings and to address some questions that no single project can answer independently.

No Charge

There is no charge for any services provided as part of the research studies. All eligible subjects receive free diagnostic and neuropsychological evaluations. No treatments are provided as part of this Network (an NICHD conference on effective treatment in autism is scheduled for 1998), but most projects are located at major centers where treatment services are available for a fee. You may participate in only one genetic study of multiplex families (families with more than one child with autism), but, in most cases, you may participate in as many of the other studies as you like. Because of research requirements, each study has eligibility criteria for participation. Genetic studies involve drawing a blood sample. The others do not.

Genome Studies of Families with More than One Child with an Autism Disorder

One of the best ways to find the genes for autism is to perform a genome-wide screen for autism susceptibility genes using DNA from families with more than one child with an autism disorder (Autism, Asperger's etc.). Two of the Autism Collaborative Network projects (U of Washington, and Yale/University of Chicago/UCLA) need your help in finding the autism gene(s) through a genome search. These CPEAs include scientists who have successfully found genes for other disorders and clinicians who are among the most experienced in the world in diagnosing autism. These projects have also met all NIH requirements for safety and preserving confidentiality of information. DNA from genetic studies will be

preserved so that it will be available for later study by these and other scientists. More than 400 families are needed.

The University of Washington, Seattle - Dr. Geraldine Dawson, Dr. Gerald Schellenberg (with the Universities of Alaska, Florida, Montana, Oregon, and Vanderbilt University (Tenn.)) To participate, contact Cathy Brock (Phone toll free, 800.994.9701; e-mail: cbrock@u.washington.edu). Participants in the study will receive free diagnostic and neuropsychological evaluations. All travel and hotel costs for multiplex families only will be paid by the study. In addition to the genetics studies, this project will study the emergence of speech and language, and brain structure and function that underlie speech and social behavior in autism. This project also needs birthday videos for children with autism who have both first and second birthday videos, especially videos of children who lost speech and social skills during the preschool years.

Yale University, New Haven, Connecticut - Dr. Fred Volkmar, Dr. Catherine Lord, and Dr. Susan Smalley (with the University of Chicago, the University of California at Los Angeles (UCLA), Oxford University, and the University of London (plus others in England, France, and Germany). Contact Kathleen Koenig, R. N. (Phone: 203.785.3488; e-mail: mikle.south@yale.edu). All subjects receive free diagnosis and neuropsychological evaluation including a parent conference and general recommendations for treatment. This project is focusing on the causes of high functioning autism and Asperger's disorder. Studies include the underlying genetics, neuropsychological profiles, and brain structures and functions for the various autism disorders. A followup study of children originally diagnosed at age 2-3 will identify early predictors of autism. The European Consortium, linked to the Autism Collaborative Network through this project, is based at Oxford and the University of London and is funded by the Medical Research Council of Great Britain and the Wellcome Fund.

Other Genetic Studies

The University of Rochester - Dr. Patricia Rodier

(with York University, Ontario, Canada)
Contact Dr. Rodier (e-mail: rodierp@ehsct7.envmed.rochester.edu or fax: 716 244 2209).

This project uses an animal model to test a new theory that autism may be caused by exposure to an environmental toxin very early in pregnancy and/or a genetic susceptibility. The studies also evaluate families with more than one child with autism for specific genetic mutations expected on the basis of this new environmental theory.

The University of California at Irvine - Dr. Anne Spence and Dr. Pauline Filipek

Contact Dr. Spence (Phone: 714- 456- 8385)
This research effort will explore the genetics of autism; investigate brain structure in autism using magnetic resonance imaging (MRI), especially changes in the brain in adolescence; and document "regression" in language and/or social behavior for children with autism whose early development was normal. The cost of diagnosis, MRI, neuropsychological and genetic evaluations for eligible children, ages 2 to pre-adolescence, will be covered by the project. The overall goal of the project is to identify "subtypes" of autism which share a common etiology (cause). These subtypes can lead us to the genes that cause autism.

The University of Utah - Dr. Reed Warren and Dr. William McMahon

(with Utah State University and the University of Iowa)
Contact Dr. William McMahon (Phone: 801 588 3559; e-mail: pcwmcmah@ihc.com).
This project tests the idea that autism is caused by an immunogenetic susceptibility that predisposes individuals to autism and may make infants susceptible to pathogens during pregnancy that would be harmless to others. This research is based on the immune and autoimmune abnormalities found in a large subgroup of persons with autism and/or their parents. The other studies in this project are focused on other aspects of subgroups in autism including the study of brain structure and function, particularly executive function, and a study of the enlarged head sizes found in autism (U of Iowa).

Autism as a Complex Information Processing Disorder

The University of Pittsburgh - Dr. Nancy Minshew and Dr. Patricia Carpenter

(with Carnegie Mellon (Pittsburgh) and Case Western Reserve (Cleveland, Ohio))

Contact Dr. Nancy Minshew, Phone: 412 624 0818; e-mail: minshewj@mxs.upmc.edu
This project tests the assumption that autism results from abnormal development and dysfunction of the prefrontal cortex. Drawing on an outstanding brain imaging and neuropsychology team, this project will examine evidence of strengths in basic brain functions and deficits in complex information processing. A cross-sectional study of adults and a longitudinal study of children will assess maturation of language, cognitive abilities, and the neural circuitry underlying both.

Language and Communication

Although the study of language and communication is an integral part of all the CPEAs, two of the projects are focused specifically on defining the developmental course and brain functions related to language and communication.

U of California, Los Angeles - Dr. Marian Sigman

Contact Margie Greenwald, (Phone: 310 825 0575; e-mail: margieg@ucla.edu)
This project will determine biological and environmental contributors to social communicative competence in autism. One study will use functional magnetic resonance imaging (fMRI) to learn how regions in the brain in autism work in tests of empathy, facial expressions, and prosody (the rhythm and accents of speech). Another study will compare two different methods for accelerating language development. Another will assess social and adaptive competence in adolescents and adults with autism whose social, communicative, and symbolic skills were measured at ages 3-5.

Eunice Kennedy Shriver Center, Waltham, Massachusetts - Dr. Helen Tager-Flusberg and Dr. Susan Folstein

(with the University of Massachusetts, and Tufts New England Medical Center)
Contact Cindy Aweimrine (Phone: 617/800 642 0180; e-mail, htagerf@shriver.org or caweimrine@shriver.org or fax: 617 642 0185).

This project will study the genetics, behavioral characteristics, developmental course, neural

processing, and neuropathology of autism, particularly as they relate to language and social understanding. This will include study of the Theory of Mind (a potential core deficit in autistic persons' inability to communicate), an in-depth study of adolescents with autism with IQ's below 40, and structural and functional imaging of language-related brain regions. In addition to free diagnostic, and neuropsychological evaluations, eligible participants will receive free language evaluations and travel costs from Massachusetts and surrounding areas to the Shriver Center (10 miles west of Boston).

Hearing in Autism Albert Einstein College of Medicine - Dr. Michelle Dunn

Contact Dr. Dunn (Phone: 718 430 2459, fax: 718 430 8785)

This project will examine the integrity of auditory processing in children with autism through behavioral (audiometric), physiologic, and electrophysiologic (event-related potentials ERP) measures, and relate it to later language development. As such, this project may represent the most thorough assessment of hearing yet undertaken in autism.

Movement and Sensory Processing

U of Colorado Health Sciences Center, Denver - Dr. Sally Rogers & Dr. Bruce Pennington

(with the University of Denver and Johns Hopkins University, Baltimore, Maryland)
Contact Dr. Sally Rogers (Phone: 303 315 8244; e-mail: Sally.Rogers@UCHSC.edu)
This project is measuring sensory processing in adults and young children with autism and Fragile X syndrome. Some of the most sophisticated brain imaging technology available, including magnetoencephalography (MEG) will be used to test hypotheses regarding auditory memory, cortical hyper-reactivity and other aspects of brain functioning in autism. A longitudinal study will measure early sensory, affective, and motor abilities of preschool children and assess their impact on later attentional and social functioning. A related study (Johns Hopkins U.) will assess language and social functioning in relatives in families with more than one child with autism.

**National Academy of Sciences/National Research Council
Commission on Behavioral and Social Sciences and Education
Division on Education, Labor, and Human Performance**

Workshop Series: Educational Interventions for Autistic Children

Summary

The National Research Council proposes to undertake an examination of research and practice in the education of children with autism. The primary focus will be children from birth to age eight and will encompass a variety of interventions and settings. Because the research base is relatively sparse, the project will be centered on a series of workshops involving researchers, educators, school administrators, specialists in autism, developmental psychologists, and policy experts in a sustained discussion of issues surrounding autism and the education of autistic children.

A steering committee will be convened to frame the issues, design and plan the workshops, commission papers, and identify the participants. Based on the workshop discussions and information submitted, the steering committee will write a report of its findings and conclusions about the current state of knowledge, pressing questions of policy, and the most compelling research needs.

The project will be carried out over a period of two years at a cost of \$500,000.

Background

It has been over 50 years since Dr. Leo Kramer, a psychiatrist at Johns Hopkins University, wrote the first paper applying the term "autism" to a group of children who exhibited a unique set of severe social, communication, and behavioral problems (Edelson, 1995). Since Dr. Kramer's initial identification and classification of autism, research and experience with autistic children have led to a better understanding of the nature of autism, a brain disorder that affects an individual's ability to communicate, form relationships with others, and respond appropriately to sensory stimulation. Individuals with autism are no longer regularly isolated in institutions. Doctors and educators now recognize that the symptoms of autism are treatable. Children with autism often attend school with other children; many autistic youth are taught skills that can help them make the transition between school and an active life in their community; adults with autism can be given supervision and training to achieve as much independence as possible. Despite these strides, there is still very little known about the causes of autism, its diagnosis remains difficult, and many strategies for educating autistic children remain untested.

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Data on the Incidence and Prevalence of Autism

Autism is found in every region of the world and in families of all racial, ethnic, religious, and economic backgrounds (National Institute of Mental Health, 1996). Many agree that autism occurs in 4.5 out of every 10,000 live births. Researchers have also estimated that 15 to 20 out of 10,000 children exhibit autistic-like behaviors. According to the Autism Society of America, almost 400,000 people in the U.S. today have some form of autism. Its prevalence rate places it as the third most common developmental disability, more common than Down's Syndrome (Autism Society of America, no date). Like other developmental disorders, autism affects males 4 times more than females (Edelson, 1995).

Data indicating the numbers of students with autism in the education system are relatively new. As a result of the 1990 Amendments to the Individuals with Disabilities Education Act (IDEA) (P.L. 101-467), the U.S. Department of Education introduced autism as a separate special education reporting category to the states in the 1991-92 school year.¹ The number of autistic students in special education has risen each reporting year. In the 1991-92 school year, states indicated that 5,415 students with autism were served in special education. By the 1995-96 school year, the numbers served rose to 28,827 (U.S. Department of Education, 1996, 1997). Many states attributed this increase to the provision of technical assistance to school districts in the identification and evaluation of students with autism (U.S. Department of Education, 1996). In addition, states indicated that autistic children were previously served and reported under other disability categories, such as "other health impaired" (U.S. Department of Education, 1996; National Information Center for Children and Youth with Disabilities, no date).

General Characteristics of Autism

Although people with autism vary greatly in individual abilities and deficits, there are common problems that can be used to characterize autism.² Social symptoms of autism include difficulty in learning to engage in human interaction and problems in interpreting what others are thinking and feeling.³ Autistic people also experience communication difficulties. Research shows that about half of the children diagnosed

¹ The Office of Special Education Programs (OSEP) in the U.S. Department of Education collects data as part of the requirement under the federal formula grant programs for special education. Each state educational agency conducts an annual count of the number of children served on December 1 of each year. The students represented by OSEP data are those who have Individualized Education Plans (IEPs) and participate in special education programs designated for the disabled under the Individuals with Disabilities Education Act (IDEA).

² Autism is often referred to as a "spectrum disorder." This means that symptoms and characteristics of autism may be present in a variety of combinations. Students with autism can exhibit behaviors associated with autism to varying degrees of severity.

³ A term often used to describe an autistic person's inability to relate to others is "theory of mind." This term refers to one's inability to realize that other people have their own unique points of view about the

with autism do not develop speech throughout their lives (National Institute of Mental Health, 1996). Some children develop a condition known as echolalia; they are only able to parrot what they hear (National Institute of Mental Health, 1996). Many children with autism are also highly attuned to sounds, tastes, textures, and smells. The brain of an autistic child is often unable to balance senses appropriately or sensations become scrambled. Children with autism may also develop dysfunctional behaviors, such as self-stimulatory behaviors (e.g., rocking), self-injury (e.g., hand biting, head banging), hyper- or hypo-activity, and attention deficits. Many autistic children also become overly insistent on routines. One possible reason for this insistence on "sameness" may be the child's inability to understand and cope with novel situations (Edelson, 1995).

Children exhibit the symptoms of autism at different points of development. In the first few years of life, some autistic toddlers reach developmental milestones, such as talking, crawling, and walking, much earlier than the average child does, whereas other autistic children are considerably delayed. Approximately one-third of autistic children develop normally until somewhere between 1 1/2 to 3 years of age; then autistic symptoms begin to emerge (Edelson, 1995).

Causes of Autism

While several older theories about the cause of autism have now been proven false--fortunately, parents are no longer blamed for their child's condition--causation is not yet well understood. Scientists do know that autism is characterized by abnormalities in the brain. MRI (Magnetic Resonance Imaging) and PET (Positron Emission Tomography) scans show stunted growth in certain nerve cells and abnormalities in the structure of the brain (National Institute of Mental Health, 1996; Seshadri, no date). Researchers are exploring different explanations for various forms of autism including genetic influences, viral infections during pregnancy, toxins and pollution in the environment, and other factors that may cause problems in normal brain development (National Institute of Mental Health, 1996; Edelson, 1995).

Diagnosing Autism

The diagnosis of autism is difficult and cannot be easily confirmed by any neurological or medical test (Boyle, no date). While several of the characteristics of autism described by Dr. Kanner in 1943 are used in diagnosing autism today, many different sets of diagnostic criteria have been tried over the years. The current set of criteria is outlined in the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) published in 1994 (Boyle, no date).⁴ DSM-IV provides a set of guidelines for professionals to use in making a clinical assessment of a child.

world. This idea has received much attention including a recent book in 1995 by Dr. Simon Baron-Cohen (*Mindblindness*, Cambridge, MA: The MIT Press) (Edelson, 1995).

⁴ According to the Autism Society of America, other diagnostic tools include the Checklist for Autism in Toddlers (CHAT), Childhood Autism Rating Scale (CARS), Parent Interviews for Autism (PIA), Gilliam

The diagnosis of autism is difficult because there are several other conditions that can cause symptoms similar to autism including hearing loss, speech problems, mental retardation, and neurological problems. The DSM-IV classifies other disorders similar to autism under a general group called pervasive developmental disorders (PDDs). According to the DSM-IV, the term PDD is not a *specific diagnosis*,⁵ but an umbrella term under which the following specific diagnoses are defined: Autistic Disorder, Rett's Disorder, Childhood Disintegrative Disorder, Asperger's Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS) (Autism Society of America, no date). Because autism is a spectrum disorder and these disorders share similar characteristics with autism, there is a great deal of disagreement among professionals about how to diagnose and label autism properly and the appropriateness of PPD as a diagnostic label (National Institute of Medicine, 1996; Autism Society of America, no date).

Educating Autistic Children

Autism has been called the "ultimate learning disability" because people with autism have great difficulty understanding language and social behavior (Moreno, 1991). The communication problems that characterize autism present multiple challenges to administrators and teachers in providing autistic children with educational services. Moreover, autistic children, like any other group of children, have a wide range of educational abilities and interests.

As educational programs for autistic students continue to expand the field's knowledge and techniques, program developers and researchers have come up with a number of strategies designed to make educational programs more effective in managing the limitations of autism. Effective programs appear to be individualized, have consistent schedules, teach tasks in a series of simple steps, implement highly structured activities, and provide regular reinforcement of behavior⁶ (National Institute of Mental Health, 1996).

While educators recognize some factors that may produce gains for autistic children, all agree that there is *no single* educational approach that can address the needs of all autistic children (Edelson, 1995). Several common approaches to the education of autistic children are outlined below:

Autism Rating Scale (GARS), and the Behavior Rating Instrument for Autistic and other Atypical Children (BRIAC).

⁵ Although the DSM-IV does not describe PDD as a diagnostic category, some children are labeled PDD (Autism Society of America, no date).

⁶ These are characteristics of what the field calls structured teaching (see Division for the Treatment and Education of Autistic and Related Communication Handicapped Children's (Division TEACCH) website at <http://www.unc.edu/depts/teacch/>).

Behavior Management: Many education programs include techniques to deal with the behavioral manifestations of autism. Some programs focus on inappropriate behavior and use applied behavior analysis to determine the cause of the behavior (Autism Society of America, no date). Other programs are based on learning new skills. Behavior programs can be implemented across home, school, and work environments.

Dr. O. Ivar Lovaas developed a behaviorist intervention for autistic children more than 25 years ago (National Institute of Mental Health, 1996). The Lovaas method involves intensive, highly structured, repetitive sequences in which a child is given a command and is rewarded each time he or she responds correctly. Some programs use this intensive approach with students for up to 40 hours a week. Some children greatly modify their behavior in response to the Lovaas technique, others are less responsive to this treatment (National Institute of Mental Health, 1996).

Communication: Many programs include methods to increase communication skills. Depending on each child's needs, speech therapy may focus on acquiring language skills or teaching sign language. Communication aides, such as electronic communication devices or picture communication boards may be used to help a person with autism communicate more effectively.

Some programs also use a controversial communication technique called facilitated communication. This approach assumes that a child will be able to communicate with the help of a "facilitator" who supports the child's arms and fingers so that he or she can type on a keyboard. While this treatment is popular with parents who seek to communicate with their autistic child, research studies suggest that the facilitator may be unknowingly directing the person's hand or arm and the typed messages reflect the facilitator's thoughts, rather than the student's (National Institute of Mental Health, 1996).

Sensory Integration Training: As noted above, an area of difficulty often present in students with autism is the integration of sensory messages. Sight, hearing, touch, smell, and taste may be affected in varying degrees. Problems with integrating sensory information are sometimes referred to as "sensory integrative dysfunction." There are different treatments available depending on the particular "sense" that is affected. For example, in auditory integration training the student listens to a variety of sounds with the goal of improving language comprehension. However, research suggests that this technique may be no more effective in improving auditory integration than having the student listen to music (National Institute of Mental Health, 1996).

Developing Social Skills: One of the main characteristics of autism is a lack of social ability or the understanding of social cues. Social skills programming may include such diverse techniques as helping an individual with autism learn to recognize facial expressions and emotions, and communicate in social situations. As with other approaches, social skills programming will vary depending on individual need.

Other examples of the wide range of approaches used in programs for autistic students include holding therapy, diet/vitamin therapy, pharmacotherapy, animal therapy, cranial sacral therapy, the Dolman/Delcato Method, and music therapy. With so many options available, many of which are controversial and lack scientific evidence to prove their effectiveness, practitioners, administrators, and parents need more information on which to base decisions about appropriate educational programs for autistic children.

Proposed Plan of Action

The National Research Council, through its Division on Education, Labor, and Human Performance in the Commission on Behavioral and Social Sciences and Education, proposes to conduct a workshop series on Educational Interventions for Autistic Children. A steering committee will be established to frame the issues, plan and carry out the workshops, commission papers, and produce a report of its findings and conclusions. The primary focus of the project will be early intervention, preschool, and school programs for children from birth to age 8.

The workshops will provide a forum for an interdisciplinary discussion of the theory, research and evaluation of educational programs for students with autism. In bringing together researchers, educators and special educators, school administrators, psychiatrists and psychologists, autism specialists, and representatives from other disciplines and interests, the workshops will encourage a joint exploration of issues related to the education and socialization of autistic children. Drawing from these discussions, the steering committee will produce a written report of its conclusions about the state of the science and practice of educational interventions for autistic children.

This proposal calls for two workshops; additional funding will be sought to enable the steering committee to undertake a third workshop.

Framing Issues

In the process of designing the workshop series, the steering committee will examine a variety of topics around which the workshops might be developed. Issue-areas the steering committee is likely to consider are:

Early Intervention Issues

If there is one topic on which there is clear consensus among scientists, clinicians, educators, service providers and parents, it is that interventions should begin early for children with autism. This is, nonetheless, a young field; research and practice are evolving rapidly and a good deal of natural and scientific experimentation is going on. As is the case with many areas of education, there is also a good deal of zealous marketing of intervention programs and strategies for which little or no evidence of effectiveness has been scientifically demonstrated (Strain *et al*, 1998).

There are many questions about early intervention strategies and programs for young children with autism that would lend themselves to examination in a workshop setting:

- What are the central medical, educational, and developmental issues in the upbringing of young children with autism?
- What is the current state of the art in early intervention? Are there programs of proven efficacy? How robust is the science base? The clinical evidence?
- Does/can common practice approach the state of the art?
- How can current research on autism strengthen early intervention programs, curricula, strategies, service delivery?
- How much is known about mapping intervention strategies onto specific diagnostic traits or constellations of traits?

Diagnosis and Classification Issues

The diagnosis of autism and the classification of autistic children for educational purposes are not without difficulties. The *diagnosis* of autism is based on clinical criteria, such as the characteristics outlined in the DSM-IV, and the professional expertise of a clinician. While there are tools to help evaluate infants and children, the diagnosis of autism remains a subjective determination based on clinical knowledge and experience. As would be expected, autistic children can be misdiagnosed--the similarity of symptoms exhibited by such conditions as Asperger's Disorder has been noted--or simply labeled PDD.

Classification decisions, while informed by diagnosis, also involve an *educational assessment* of a child's needs and deficits and development of an Individualized Education Plan (IEP) for the student or an Individualized Family Service Plan (IFSP) for infants to age three, based on the provisions of the IDEA. Hence a categorical list of federally recognized disabilities, only some of which coincide with clinical definitions of disorder, enters the discussion. Special education researchers have long expressed concern about the poor correlation between some disability categorizations and treatments provided to special education students (see Reschly, 1996). It is not clear that mislabeling a child as having Asperger's Disorder or use of the PDD disability category would significantly change the way in which autistic children are educated in the present state of the art (National Institute of Mental Health, 1996). Nevertheless, some express the concern that labels such as PDD "may keep [an autistic] child from receiving the full range of specialized educational services available to children diagnosed with autism" (National Institute of Mental Health, 1996:21). Concern has also been expressed that such labels may give parents false hope that their child's difficulties are temporary.

Until much more is known about the causes and neurobiology of autism, there will continue to be ambiguities about its diagnosis and about designing appropriate educational interventions. An interdisciplinary discussion and exchange of ideas among

clinicians, educators, and policy makers could help expand understanding of such issues as:

- the strengths and shortcomings of current diagnostic tools;
- the impact of misdiagnosis on a student's access to specialized education services;
- the clinical diagnosis of autism and educational planning for autistic children;
- the increasing use of PDD as a label and its implications for the education of autistic children;
- the impact of diagnostic and categorical labels on parent/teacher expectations of student abilities and educational outcomes; and
- the functional capacities of children with autism.

The Rights of Autistic Children to an Appropriate Education and Untested Educational Approaches

Under the Individuals with Disabilities Education Act (IDEA), children with autism are entitled to a free and appropriate education. IDEA stipulates that autistic children are entitled to individualized educational services outlined in an Individualized Education Plan (IEP) or Individualized Family Service Plan (IFSP), that educational services must be implemented in the least restrictive environment, and their rights are protected through procedural safeguards (National Research Council, 1997). Challenges to the design and delivery of services to autistic children are becoming increasingly frequent: "In the past 2 years, more than two dozen hearing officers or federal judges have decided that IEPs for specific children with autism were not designed in such a way as to achieve reasonable educational benefit" (Strain et al., 1998:8). In such a litigious environment, parents and schools may spend a great deal of time and energy engaged in adversarial relationships, rather than concentrating on the educational needs of the child.

The surge in competing, costly, and often untested educational programs for autistic students further complicates the planning and delivery of appropriate educational services for autistic children. There is no standard, universally accepted approach to educating autistic children. Rather, there is a wide array of programs that parents can request for their child's IEP (or IFSP). Many such programs make claims of outcomes that have not been tested; many have no basis in theory or rest on an unexamined theoretical base.

Observers fear that many school districts, confronted with the possibility of costly litigation, are paying for programs that have not been shown to be effective. This is bad for the child and does not contribute to progress in finding effective interventions. Further, such programs can be highly specialized and intensive, and thus costly, creating a fiscal burden for districts and states.

Many issues growing out of the interplay of these factors warrant sustained discussion among researchers, educators, school administrators, and advocates. Participants in one or more workshops might consider such matters as:

- the wide variety of education programs for autistic students;
- the effectiveness of education programs for autistic students and the science base for these programs;
- the ability of the current IEP process to adequately plan and deliver appropriate educational strategies to autistic students;
- the current legal cases challenging educational services provided for autistic children;
- the cost of litigation for school districts;
- strategies to encourage parents, teachers, and other school officials to work together cooperatively in developing a student's IEP and to examine whether such strategies reduce litigation;
- strategies, such as developing standards of practice, to assist schools in identifying and validating promising programs; and
- strategies for enhancing access to the general education curriculum.

Mainstreaming Autistic Students

Some propose that mainstreaming offers autistic students increased opportunities for social interaction with peers (Hocutt, 1996). This view finds general support in research suggesting that children with disabilities enrolled in integrated early childhood programs develop higher levels of social play and appropriate social interaction, and are more likely to initiate interaction with peers (Strain et al., 1998). However, concern is often raised about the effects of mainstreaming on the development of severely handicapped students, including autistic children.⁷ Many believe that autistic children need more control over routine, classroom structure, and intensive social training than can be provided in a regular classroom. Further, some argue that there is no compelling research evidence that placement, rather than instruction, is critical to a student's academic or social success (Hocutt, 1996; Diamond, et al, 1994).

There is a need for better understanding about the effectiveness of mainstreaming for students with disabilities, especially autistic students. The quality of a student's experience in an integrated setting implies far more than a placement decision. The difficulty autistic children have in communicating with others raises questions about their probability of flourishing in highly complex social situations such as general education

⁷ More than half of autistic students are placed in self-contained classrooms that serve other students in special education, rather than in regular classrooms or in classrooms tailored to meet their specific needs. During the 1993-94 school year, 10.85 percent of autistic students ages 6-11 were in regular class setting, 9.12 percent of students ages 12-17, and 4.18 percent of students ages 18-21 (U.S. Department of Education, 1996: 68).

classrooms and whether there are accommodations that would make that outcome more likely (Sorensen, 1996).

An examination of the accumulated experience with mainstreaming might provide useful insights on such issues as:

- current methods used in educational programs in connection with mainstreaming;
- the academic and social progress of autistic students in integrated environments;
- the costs of implementing current programs used in mainstreaming autistic students;
- the level of support autistic children need to succeed in an integrated classroom environment; and
- the level of support school staff and families need to mainstream an autistic child.

Assistive Technology for Autistic Students

Many educators believe that technology can play a key role in education by tailoring the learning experience for individual students, providing students with access to resources and expertise outside of the school, and assisting schools in managing and guiding the learning activities of their students (Glennan and Melmed, 1996). There have been large monetary investments in the last few years to increase student access to technology.

The first extensive use of computers provided drill and practice for individual students. Such drill and practice software eventually came to include features that could guide students through extensive bodies of material (Char, 1990). Such technology is used with autistic children to develop communication skills through sensory integration. Computer technology is also used as a tool for structured learning, a teaching approach used with autistic students.

Despite the enthusiasm for the use of technology in schools, there are several issues surrounding the use of technology in general education that are amplified when examining the use of technology with children in special education. Researchers and policymakers concede that more research on the broad variety of technology's educational effects is needed. In the 1990 amendments to the IDEA, Congress made schools responsible for providing assistive technology to students in special education settings and helping to select devices and equipment appropriate for each child's use (Martin et al., 1996; Parette et al., 1993). Because information about technology and training in its use is limited (Parette et al., 1993), schools, teachers, IEP team members, and parents need more information on the types of technology available and the impact

assistive technology has on the achievement of special education students, including autistic children.

One possible workshop theme, therefore, is the potential uses of technology in educating young children with autism, including:

- use of technology in education programs for autistic students and the ways in which technology can be better integrated into educational programs;
- autistic students' access to assistive technology;
- cost of using assistive technology with autistic students; and
- available training for teachers and parents in using assistive technology with autistic students.

Products

The products from this activity include, in the first instance, the workshop discussions themselves. At present, two workshops are planned. If supplemental funding can be generated, a further workshop will be added. The primary written product will be a report by the steering committee, based on the workshop discussions and commissioned papers, of its findings and conclusions about the current state of knowledge, pressing questions of policy, and the most compelling research needs. The papers commissioned for the workshops will also be made available to the sponsor. If supplemental funding can be arranged, the steering committee will consider whether the papers are of sufficient interest to a broader community to be published.

NAS/NRC STUDY PROCEDURES

Studies undertaken by the National Academy of Sciences (NAS)/National Research Council (NRC) are carried out by committees of volunteer experts working with professional staff in accordance with procedures of the National Research Council. These procedures are designed to ensure the highest levels of scientific competence, to protect against bias or conflict of interest, and to preserve the independence and objectivity of the committee process.

Study Procedures

The National Research Council has no research laboratories; rather, it synthesizes, analyzes, and evaluates research from relevant scientific disciplines that can be brought to bear on questions of national importance. Through this process, the NRC provides expert advice on the interpretation of bodies of scientific work and the application of science to particular problems of public policy; it assists in the evaluation of government agencies or programs, building of research agendas, and setting of priorities for scientific work and its application to national problems.

Committees and Panels: The Academy's work is carried out by interdisciplinary committees and panels appointed to conduct particular projects. The Academy has a proven record of assembling scientific experts of the highest caliber to address critical national problems.

Members of committees are appointed by the chairman of the National Research Council, who serves simultaneously as president of the National Academy of Sciences. The search for candidates is carried out by NRC staff, who review the scholarly literature and consult widely with Academy members, related boards and committees within the NRC, knowledgeable authorities in the relevant disciplines, and professional associations to discuss the more important areas of expertise to be represented on the committee and to solicit recommendations.

Because of the institution's commitment to independence and objectivity in carrying out its work, governmental agencies and other sponsors are precluded from selecting committee members. However, NRC staff may, and often do, ask sponsors to suggest people for consideration.

Professional Staff: Each committee is assisted in its work by highly qualified professional staff members who bring substantive expertise and interdisciplinary interests to the management of the committee process. It is the responsibility of the staff to create the dispassionate and objective atmosphere in which the NRC deliberative process takes place.

Protection Against Bias and Conflict of Interest: A major concern in forming study panels is assuring appropriate balance and protecting the committee from conflicts of interest. At the time of appointment, each new member is required to fill out a form on Potential Sources of Bias and Conflict of Interest, on which professional, consulting, and financial connections are listed and pertinent intellectual positions or public statements are described. This information is discussed by the committee as a whole at the first meeting (and annually thereafter) and reviewed by appropriate officials of the NRC.

NRC Approval, Oversight, and Review Procedures

The National Research Council process guides the acceptance of subjects for study by the institution. In addition, the NRC process subjects the work products of the institution to critical review by a body of peers.

Project Approval: Acceptance of a subject for study involves several stages, of which the last, and most critical, is approval by the NRC Governing Board. In its decision to accept or decline a project, the Governing Board considers the importance and timeliness of the question, its background, the audience, its likely impact, and the competence of the institution to take on the task.

Oversight: Once a project is under way, responsibility for ensuring adherence to the NRC process lodges primarily with the cognizant unit of the NRC--in this case, the Division on Education, Labor, and Human Performance within the Commission on Behavioral and Social Sciences and Education. This includes oversight of procedures for appointing members to the committee, substantive quality control, and monitoring the timely completion of the project.

Report Review: The final stage of the NRC process, that of review, falls under the auspices of the Report Review Committee (RRC), whose task it is to vouch for the credibility of the committee's work by verifying that the committee has fully considered the evidence pertinent to the issue under review, that its conclusions and recommendations are supported by the body of the report, that the report is clearly written and responsive to the committee's charge, and that its level of discourse is appropriate for the intended audience.

Every NRC committee report is reviewed by individuals who are not involved in the authoring committee's work. A report may not be released to an agency or the public until the RRC chair, or a designated person, signifies that the institutional review process has been completed satisfactorily.

Reports resulting from this effort shall be prepared in sufficient quantity to ensure their distribution to the sponsor and to other relevant parties, in accordance with Academy policy. Reports may be made available to the public without restrictions.

FEDERAL ADVISORY COMMITTEE ACT

The Academy has developed interim policies and procedures to implement the Federal Advisory Committee Act, 5 U.S.C. § 1 et seq. (FACA), as amended by the Federal Advisory Committee Act Amendments of 1997, H.R. 2977, signed into law on December 17, 1997 (FACA Amendments). The FACA Amendments exempted the Academy from most of the requirements of FACA, but added a new Section 15 that includes certain requirements regarding public access and conflicts of interest that are applicable to agreements under which the Academy, using a committee, provides advice or recommendations to a Federal agency. In accordance with Section 15 of FACA, the Academy shall deliver along with its final report to the U.S. Department of Education a certification by the Responsible Staff Officer that the policies and procedures of the National Academy of Sciences that implement Section 15 of FACA have been complied with in connection with the performance of the contract/grant/cooperative agreement.

Public Information About the Project

The NRC will post on its web site (<http://www.nas.edu>) a brief description of the project, as well as committee appointments with short biographies of the members,

meeting notices, and other pertinent information, to afford the public greater knowledge of our activities, and an opportunity to make comments.

The web site will also include an ongoing record of compliance to the requirements of Section 15 of the Federal Advisory Committee Act Amendments of 1997, and a certification of compliance will be provided when the study is completed.

Estimate of Costs

The total estimate of costs for an activity that includes two workshops and takes place during the 24-month period August 1, 1998 through July 31, 2000, is \$500,000. This amount is requested from the Department of Education, Office of Special Education Programs. Supplemental funding will be sought from other sources for an additional workshop.

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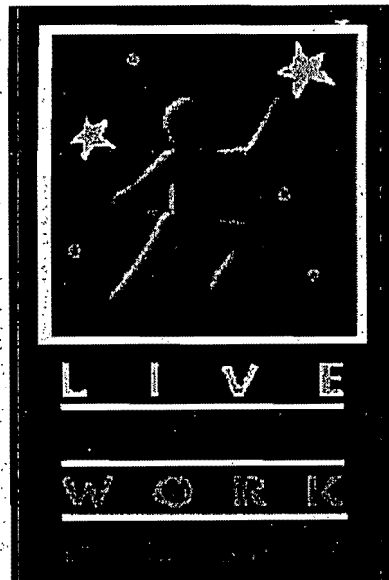
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Institutes of Higher Education Training Projects

**With A Focus On Serving Young Children With
Autism Spectrum Disorders & Their Families**

**Funded by the Office of Special Education
US Department of Education**



Vermont Rural Autism Project:

Preparing Speech-Language Pathologists and Early Childhood Providers to Serve the Needs of Children with Autism Spectrum Disorders in Rural Settings

Personnel Preparation Project

CFDA No: 84.029A

Fiscal Agency: The University of Vermont (VT-RAP)

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Purpose: The purpose of this project is to provide interdisciplinary preservice preparation for speech-language pathologists (SLPs) at both a masters and specialist level, and interdisciplinary preservice preparation for early childhood special educators (ECSEs) at a specialist level to serve children with autism spectrum disorders (ASD) and their families in rural settings. Further, through collaboration with and financial support from the Vermont State Department of Education-619 Preschool Program, the Family, Infant and Toddler Project of Vermont (Part H), and Social and Rehabilitative Services-Child Care Services Division, this project includes preservice preparation for related services personnel (e.g., social workers, child care and respite providers, psychologists, occupational therapists, physical therapists, mental health workers, nurses, early interventionists, community resource parents, etc.) at a specialist level. A total

Target: A total of 16 interdisciplinary, family-centered, community-based, specialists are prepared each year for a total of 48 specialists trained over a three-year period.

Approach: Training is accomplished through an 18 credit competency-based educational program involving a two course sequence offered through the University of Vermont's distance learning technology; a Summer Regional Institute with the participation of regional and national experts in ASD; a three semester sequence of clinical study in ASD including respite for families, community-based assessment and intervention; and leadership activities in the area of care coordination, consultation, technical assistance, in service training and transition planning. The innovative framework for clinical study in ASD allows specialist level trainees to continue their jobs supporting the children they serve while at the same time increasing their opportunities for specialist level training in ASD. This training framework also supports the development of specialist level teams in ASD across the five major regions of the state over the three years of the project.

The George Washington University:

The Low Incidence Disabilities Project Master's Degree Training in Infant Special Education with an Emphasis in Low Incidence Disabilities

Personnel Preparation Project

CFDA No. 84029A

Fiscal Agency: The George Washington University, Infant and Early Childhood Special Education Programs

Marian Jarrett

Project Director

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Purpose: The Low Incidence disabilities Project will train master's degree students as early interventionists with the unique skills and abilities to serve infants and toddlers with the low incidence disabilities of autism/multisystem developmental disorders (MSDD) and significant neurobehavioral disorders (SNBD). This 39-hour master's degree program will address the urgent education and training needs in the area of low incidence disabilities by providing a coordinated program of training experiences that focuses on the current challenging and emerging issues facing the field.

Target: To recruit and enroll 39 master's degree students from diverse backgrounds in the field of Early Childhood Special Education;

Approach: The project is based in a firm commitment to provide family-centered, individually appropriate services to infants in natural settings. The curriculum will include recent changes and emphasis in Part C of the 1997 Amendments to IDEA, standards for early intervention personnel promulgated by national organizations, and knowledge about the theoretical basis of specific interventions; research results and the efficacy of intervention, and the outcomes for infants and toddlers with MSDD and SNBD and their families. Professional development partnerships will be established in order to provide students with quality internship placements and professional development activities to the community-based early intervention partners. Students will conduct action research projects based on the expressed needs of the early intervention community. Action research results will be presented at annual research-to-practice Regional Forums along with current findings from experts in the field, university faculty and professionals developmental partners.

Student outcomes will be evaluated through the traditional methods of performance in coursework and practica and internships. Additionally, students will be required to complete a Professional Portfolio based on program competencies reflective of the standards of DEC, NAEYC, and NBPTS and integrating Competencies specific to the MSDD and SNBD populations. The curriculum will be evaluated and modified based on feedback from current students, program graduates, the advisory committee, professional development partners, and area employers.

University of North Carolina at Chapel Hill:

Interdisciplinary Preparation for Working with Young Children with Low Incidence Disabilities and Their Families: Collaboration Across three Disciplines and Three Disability Areas

Personnel Preparation Project

Grant No. H029G70177

Fiscal Agency: The University of North Carolina at Chapel Hill

Elizabeth Crais and Harriet Boone

Project Co-Directors

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Purpose: In the effort to provide effective service delivery to children with low incidence disabilities and their families, the University of North Carolina at Chapel Hill will develop a collaborative project among three master's degree programs. This training will enhance opportunities for students to gain interdisciplinary academic and field-based experiences in working with young children with low incidence disabilities and their families. Students will be prepared to work in a collaborative and interdisciplinary manner with children, parents, and other professionals.

Target: Master's Students majoring in special education, speech and hearing sciences, and occupational therapy at the University of North Carolina at Chapel Hill;

Approach: The project will offer interdisciplinary training opportunities, coursework, and practicum experiences for students in special education, speech and hearing sciences, and occupational therapy to specialize in working with young children with autism, hearing impairments, or severe physical impairments. Students will participate in seminars focusing on children with low incidence disabilities and their parents and in research and field based activities related to these children and their families. Program graduates with a specialization in working with young children with autism, hearing impairments, or severe physical impairments.

Vanderbilt University:

Preparation of Communication Specialists to Serve Young Children with Autism Spectrum Disorders: Speech Pathology and Audiology

Personnel Preparation Project

Grant No.

Fiscal Agency: Vanderbilt University, Division of Hearing and Speech Sciences

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Purpose: Appropriate identification, assessment and management of children with autism spectrum disorders is complicated and requires the cooperative efforts of skilled, well trained professionals in the disciplines of education, psychology, and communication disorders.

Unfortunately, graduates in communication disorders seldom receive adequate preparation for meeting the special needs of young children with autism. This personnel preparation project will support graduate level personnel with special training in autism spectrum disorders.

Target: The proposed plan is to enroll eight graduate students each year (six funded), four in speech/language pathology and four in audiology, over a three year period.

Approach: Specifically, the project will focus on children with autism—two to seven years of age and their families—and a multidisciplinary/interdisciplinary approach to the identification, assessment, and management of children with autism. To accomplish this end, resources from three departments associated with Vanderbilt University will be utilized to provide students with a comprehensive training program; Special Education, Pediatrics, and Hearing and Speech Sciences. The program will feature a combination of didactic coursework and related field practicum. The Bill Wilkerson Center, a large multifaceted facility dedicated to serving children and adults with communication disorders, will be the primary resource for student practicum opportunities. The Division of Hearing and Speech Sciences will serve as the host department.

University of Wisconsin-Madison:

Educational Leadership Preparation Program to Support Learners With Severe Communication/Behavioral Disorders and Autism in Heterogeneous and Inclusive Settings

Personnel Preparation Project

Grant No.

Fiscal Agency: University of Wisconsin-Madison

Department of Special Education and Rehabilitation Psychology

Anne Donnellan

Project Director

University of Wisconsin-Madison

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Purpose: To extend and expand a successful, interdisciplinary doctoral level training project to produce educational leaders for the new era in education, maintaining the best of the last but acknowledging that new strategies will be necessary to address the needs of the new Century. If inclusion is a goal and diversity is to be supported, the needs of individuals with labels such as autistic, and other severe communication/behavioral challenges must be addressed innovatively.

Target: At least nine qualified teachers and related service personnel will be trained to develop supportive and collaborative relationships with learners, teachers, parents and related staff in regular and special education.

Approach: Training emphasis has shifted from specialized services in integrated setting to full inclusion, support, and participation. Trainees will now work with culturally diverse, internationally recognized leaders in regular and special education, curriculum, communication, movement/neuromotor disturbance, positive behavioral support, and service delivery from early childhood through transition to adult services. Trainees will be affiliated with our RRTC in Career Development for post-school issues and with InterACT/Trace Center project to allow specialization in augmentative and assistive technology. They will become leaders, prepared via a broad conceptual and experiential base in this personalized training program, presenting a unique and critically needed understanding of diversity, community, communication and of the interface of severe disability with minority and cultural issues.

The University of Missouri:

Preparing Special Educators to Work with Young Children with Autism and their Families

Personnel Preparation Project

Grant/Contract Number: H325A990034

Fiscal Agency: University of Missouri, College of Education

Tim Lewis

Project Director

The University of Missouri

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Purpose: This project will meet the need for early interventionists and early childhood special educators who can meet the needs of children with autism and their families. The program of study expands the early childhood special education program at the University of Missouri to include coursework, practica, consultation/collaboration activities, and other professional development experiences in the area of autism.

Target: Approximately 39 Master's level students will be trained through the project.

Method: Students in the program will be required to engage in professional development activities such as program development, serving on planning committees, and attending and presenting at professional conferences and workshops. Parents and professionals with experience and expertise in the field throughout the state of Missouri will participate in the development, implementation, and the evaluation of the program, providing a unique training experience for students.

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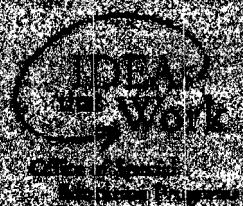
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NECTAS
Resource Collection
on
Autism Spectrum
Disorders

Kathy T. Whaley & Evelyn Shaw
Editors



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