



Educating Children with Autism

Committee on Educational Interventions for Children with Autism, National Research Council

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Educating Children with Autism

Committee on Educational Interventions for Children with Autism

Catherine Lord and James P. McGee, editors

Division of Behavioral and Social Sciences and Education

National Research Council

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Educating Children with Autism
<http://www.nap.edu/catalog/10017.html>

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Preface

John Brian Harley, a British geographer, described the process of making a map as the social construction of knowledge to facilitate understanding. In many ways, the preparation of this report seemed like that of making a map, not to direct, but to organize and represent information to help progress through the many scientific findings and unknowns in the field of early education in autism. At the request of the U.S. Department of Education's Office of Special Education Programs, this project was undertaken by the National Research Council to consider the state of the scientific evidence of the effects of early educational intervention on young children with autistic spectrum disorders. In any such project, the questions become as important as the answers. Our committee represented many different fields—including clinical and developmental psychology, special education, speech and language pathology, psychiatry, and child neurology—and we elected to organize our report around the questions that we defined as most important for our areas of inquiry; these questions demand multidisciplinary attention. We attempted to provide a “map” for each of these questions that represented scientific literature from our respective fields.

The questions cover epidemiology, family support, diagnosis and screening, assistive technology, characteristics of autism, features of intervention programs, and how instructional strategies have been put together in comprehensive programs. The questions also include issues in public policy, personnel preparation, and future research.

In elementary school, children are first taught the scientific principles of experimentation and replication. Experimental methods are at the core

of the systematic collection and evaluation of knowledge that is science. Yet as Richard Horton recently said, in an article about the future of academic medicine, “. . . straightforward observations rather than intricate experimentation often produce the significant step forward,” steps that could then be tested through experimental methods. Our committee believed strongly that we needed to consider the insights provided by systematic observations, as long as the methods for such observations were detailed sufficiently enough to permit us to consider factors that might influence interpretations of the results. Similar to the recent criteria for evaluating treatment guidelines proposed by the American Psychological Association, we elected to focus on convergence and divergence of findings and to evaluate strengths and biases of sources of information, to best represent the current questions and state of evidence concerning the effectiveness of early education in autism.

This report presents the results of the committee’s deliberations. We hope it will have a broad audience, including educators and other professionals who work with and who carry out research with children with autistic spectrum disorders and their families, parents and family members, legislators and other policy makers, and advocates.

Many individuals have made contributions to the panel’s thinking and to various sections of this report by serving as presenters, advisers, and liaisons to useful sources of information. The committee is grateful to Gail Houle, at the Department of Education’s Office of Special Education Programs, for her continuous support, encouragement, and generous sharing of information most useful to the committee; and to Louis Danielson, at the Department of Education, for his workshop presentation of relevant data.

The committee thanks the following authors, who prepared commissioned papers and presented them at workshops sponsored by the committee: Grace Baranek, University of North Carolina; Eric Fombonne, King’s College London; Howard Goldstein, Florida State University; Myrna Mandlawitz; Scott McConnell, University of Minnesota; Pat Miranda, University of British Columbia; Marian Sigman, University of California-Los Angeles; Rutherford Turnbull, University of Kansas; Robert Horner, University of Oregon; Phillip Strain, University of Colorado-Denver; Edward Carr, State University of New York at Stony Brook; Connie Kasari, University of California-Los Angeles; Joicey Hurth, Donald Kates, and Kathy Whaley, NECTAS; and Mark Wolery, University of North Carolina. The papers prepared by these authors are available through the National Research Council’s unit on Behavioral, Cognitive, and Sensory Sciences and Education.

The committee also thanks the following program directors who responded to our request for data concerning their programs: Glen Dunlap and Lise Fox, Center for Autism and Related Disorders, University of

South Florida; Stanley Greenspan, George Washington University Hospital; Lynn Koegel and Robert Koegel, Graduate School of Education, University of California, Santa Barbara; O. Ivar Lovaas, University of California-Los Angeles; Gary Mesibov, TEACCH, University of North Carolina; Raymond Romanczyk, Institute for Child Development, Children's Unit for Treatment and Evaluation, State University of New York at Binghamton; and Phillip Strain, Professor of Educational Psychology, University of Colorado-Denver.

We also thank the following invited participants who attended the committee's workshops and offered valuable input to its proceedings: Doris Allen, JCC on the Palisades Therapeutic Nursery; Gina Green, Eunice Kennedy Shriver Center; Cathy Pratt, Indiana Resource Center for Autism; Serena Wieder, Interdisciplinary Council on Developmental Disorders; and Isabelle Rapin, Albert Einstein College of Medicine.

This report has been reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise, in accordance with procedures approved by the Report Review Committee of the National Research Council (NRC). The purpose of this independent review is to provide candid and critical comments that will assist the institution in making the published report as sound as possible and to ensure that the report meets institutional standards for objectivity, evidence, and responsiveness to the study charge. The review comments and draft manuscript remain confidential to protect the integrity of the deliberative process.

We thank the following individuals for their participation in the review of this report: H. Carl Haywood, Departments of Psychology and Neurology (emeritus), Vanderbilt University; Susan Hyman, Strong Center for Developmental Disabilities, University of Rochester; Linda J. Lotspeich, Division of Child and Adolescent Psychiatry and Child Development, Stanford University School of Medicine; Edwin W. Martin, Division for Learning Disabilities, Council for Exceptional Children, Arlington, VA; Nancy Minshew, Department of Psychiatry, University of Pittsburgh; Michael Rutter, Social, Genetic, and Developmental Psychiatry Research Center, Institute of Psychiatry, London, England; Stephen R. Schroeder, Schiefelbusch Institute for Life Span Studies, University of Kansas; and Linda R. Watson, Division of Speech and Hearing Sciences, Department of Allied Health Sciences, University of North Carolina at Chapel Hill.

Although the reviewers listed above have provided many constructive comments and suggestions, they were not asked to endorse the conclusions or recommendations nor did they see the final draft of the report before its release. The review of this report was overseen by Richard Wagner, Department of Psychology, Florida State University, and Eleanor Maccoby, Department of Psychology, Stanford University (emerita). Appointed by the National Research Council, they were responsible for mak-

ing certain that an independent examination of this report was carried out in accordance with institutional procedures and that all review comments were carefully considered. Responsibility for the final content of this report rests entirely with the authors.

This report is the collective product of the entire panel, and each member took an active role in drafting sections of chapters, leading discussions, and reading and commenting on successive drafts. In particular, Marie Bristol-Power assumed major responsibility for the chapter on problem behaviors, Pauline Filipek on sensory and motor development, James Gallagher on public policy and personnel preparation, Sandra Harris on the role of families, Gail McGee on comprehensive programs and adaptive behavior, Samuel Odom on research methodology and problem behaviors, Sally Rogers on social development and instructional strategies, Fred Volkmar on diagnosis and prevalence, and on cognitive development, and Amy Wetherby on development of communication. Joanne Cafiero contributed significant sections on assistive technology, and Alan Leslie added key discussions on cognitive development. Fred Volkmar also performed detailed reviews of the report drafts, contributing additional valuable insights and information.

Staff at the National Research Council made important contributions to our work in many ways. We express our appreciation to Christine Hartel, director of the Board on Behavioral, Cognitive, and Sensory Sciences, for her valuable insight, guidance, and support; and to Alexandra Wigdor, former director of the Division on Education, Labor, and Human Performance, for establishing the groundwork and direction of the project. We offer major thanks to Nathaniel Tipton, the panel's project assistant, who was indispensable in organizing meetings, arranging travel, compiling agenda materials, conducting extensive outreach with the interested community, copyediting and formatting the report, and managing the exchange of documentation among the committee members. We are deeply indebted to Eugenia Grohman, who significantly improved the report by dedicated application of her extraordinary editing skills. We also thank Amanda Taylor, at the University of Chicago, for her untiring and competent support of many aspects of the activities of the committee Chair.

Catherine Lord, *Chair*
James P. McGee, *Study Director*
Committee on Educational Interventions for
Children with Autism

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Executive Summary

Autistic spectrum disorders are present from birth or very early in development and affect essential human behaviors such as social interaction, the ability to communicate ideas and feelings, imagination, and the establishment of relationships with others. Although precise neurobiological mechanisms have not yet been established, it is clear that autistic spectrum disorders reflect the operation of factors in the developing brain. Autistic disorders are unique in their pattern of deficits and areas of relative strengths. They generally have lifelong effects on how children learn to be social beings, to take care of themselves, and to participate in the community. The autism spectrum occurs along with mental retardation and language disorder in many cases. Thus, educational planning must address both the needs typically associated with autistic disorders and needs associated with accompanying disabilities.

Education, both directly of children, and of parents and teachers, is currently the primary form of treatment for autistic spectrum disorders. The education of children with autistic disorders was accepted as a public responsibility under the Education of All Handicapped Children Act in 1975. Despite the federal mandate, however, the goals, methods and resources available vary considerably from state to state and school system to school system. In the last few years, due to a confluence of factors, courts have become increasingly active in determining the methods and resources allocated by school systems for the education of young children with autistic spectrum disorders.

COMMITTEE'S CHARGE

At the request of the U.S. Department of Education's Office of Special Education Programs, the National Research Council formed the Committee on Educational Interventions for Children with Autism and charged the committee to integrate the scientific, theoretical, and policy literature and create a framework for evaluating the scientific evidence concerning the effects and features of educational interventions for young children with autism. The primary focus of the charge was early intervention, preschool, and school programs designed for children with autism from birth to age 8. The charge included specific suggestions to examine several issues pertaining to education of children with autism: early intervention, diagnosis and classification, the rights of children with autism under the Individuals with Disabilities Education Act, inclusion, and assistive technology.

The committee's key conclusions and recommendations are summarized below, organized by the significant issues relevant to educational interventions for young children with autistic spectrum disorders. Each section begins with the key questions the committee addressed. The final chapter of this report presents the committee's complete conclusions and recommendations.

DIAGNOSIS, ASSESSMENT, AND PREVALENCE

What is the role of diagnosis, classification, and assessment in providing appropriate educational services to young children with autistic spectrum disorders? Are the specific deficits associated with a diagnosis or educational classification of autistic spectrum disorder important to planning and implementing educational interventions?

Autistic spectrum disorders vary in severity of symptoms, age of onset, and the presence of various features, such as mental retardation and specific language delay. The manifestations of autistic spectrum disorders can differ considerably across children and within an individual child over time. Even though there are strong and consistent commonalities, especially in social deficits, there is no single behavior that is always typical of autism or any of the autistic spectrum disorders and no behavior that would automatically exclude an individual child from diagnosis of autistic spectrum disorder. Because of the continuity across autistic spectrum disorders, this report addresses both autistic disorder specifically (referring to the more narrowly defined syndrome) and autistic spectrum disorder, (including autistic disorder, pervasive developmental disorder-not otherwise specified [PDD-NOS], Asperger's Disorder, and

Childhood Distintegrative Disorder). Because of its special characteristics, Rett's syndrome is not specifically considered in this report, though children with Rett's syndrome may require similar services to children with autism in some circumstances.

It is clear that autistic spectrum disorders have effects on development in ways that affect children's educational goals and the appropriate strategies to reach them. It is also clear that deficits in language development, nonverbal communication, cognitive abilities, and other areas have distinct effects on behavior and outcome in ways that have implications for the educational goals of children with autistic spectrum disorders, as well as other children. However, it is not yet clear the degree to which specific educational goals and strategies are associated with particular diagnoses within the autism spectrum, such as Asperger's Disorder, Childhood Disintegrative Disorder, or PDD-NOS, once factors such as language development and cognitive abilities are taken into account. Although experienced clinicians and educators can reliably identify the constellation of behaviors that define autistic spectrum disorders even in very young children, distinctions among "classical" autism and atypical autism, PDD-NOS, and Asperger's Disorder are not nearly as reliable. Thus, though the identification of categories within the autism spectrum is necessary for some research purposes and is an important area for research, the educational and clinical benefit of making such distinctions is not yet clear. Altogether, the most important considerations in devising educational programs for children with autistic spectrum disorders have to do with recognition of the autism spectrum as a whole, with the concomitant implications for social, communicative, and behavioral development and learning, and with the understanding of the strengths and weaknesses of the individual child across areas of development. A child who receives a diagnosis of any autistic spectrum disorder should be eligible for special educational programming under the educational category "autism" regardless of the specific diagnostic category within the autism spectrum.

The committee recommends that children with any autistic spectrum disorder (autistic disorder, Asperger's disorder, atypical autism, PDD-NOS, childhood distintegrative disorder), regardless of level of severity or function, be eligible for special education services within the category of autism.

With adequate time and training, the diagnosis of autism can be made reliably in 2-year-olds by professionals experienced in the diagnostic assessment of young children with autistic spectrum disorders, and children are beginning to be referred even before age two years. Many families express concern about their children's behavior, usually to health

professionals, even before this time, and more children are being referred for specific educational interventions for autistic spectrum disorders. However, diagnostic and screening instruments effective with children under age 2 have not yet been identified. Although children with autistic spectrum disorders share some disabilities with children with other developmental disorders, they offer unique challenges to families, teachers, and others who work with them, particularly in nonverbal and verbal communication and behavioral problems.

The committee recommends that the National Institutes of Health and the Department of Education's Office of Special Education Programs, in cooperation with professional organizations and through support for research and training, promote early identification, appropriate screening, and multidisciplinary assessment for young children with autistic spectrum disorders, as is done for children with vision or hearing problems. In addition, because of variability in early diagnosis and test scores, young children with autistic spectrum disorders should always receive an appropriate follow-up diagnostic and educational assessment within 1-2 years after initial evaluation.

ROLE OF FAMILIES

What are the needs of families of children with autistic spectrum disorders and how can they effectively participate in education and intervention?

Having a child with an autistic spectrum disorder is a challenge for any family. Involvement of families in the education of young children with autistic spectrum disorders can occur at multiple levels. Parents can learn to successfully apply skills to changing their children's behavior. Parents' use of effective teaching methods, support from within the family and the community, and access to balanced information about autistic spectrum disorders and the range of appropriate services can contribute to successful child and family functioning. It is crucially important to make information available to parents to ensure their active role in advocacy for their children's education.

The committee recommends that families' participation should be supported in education through consistent presentation of information by local school systems, through ongoing consultation and individualized problem solving, and through the opportunity to learn techniques for teaching their children new skills and reducing behavioral problems. Although families should not be expected to provide the majority of educational programming for their child, the parents' concerns and perspectives should actively help shape educational planning.

GOALS FOR EDUCATIONAL SERVICES

What are appropriate goals for educational services provided to young children with autistic spectrum disorders, and how are the goals best measured as outcomes in scientific studies, so that effectiveness of various programs may be determined?

At the root of questions about the most appropriate educational interventions for autistic spectrum disorders are differences in assumptions about what is possible and what is important to give students with these disorders through education. The appropriate goals for educational services for children with autistic spectrum disorders are the same as those for other children: personal independence and social responsibility. These goals imply progress in social and cognitive abilities, verbal and nonverbal communication skills, and adaptive skills; reduction of behavioral difficulties; and generalization of abilities across multiple environments.

A large body of research has demonstrated substantial progress in response to specific intervention techniques in relatively short periods of time (e.g., several months) in many specific areas, including social skills, language acquisition, nonverbal communication, and reductions in challenging behaviors. Longitudinal studies over longer periods of time have documented changes in IQ scores and in core deficits (e.g., joint attention), in some cases related to treatment, that are predictive of longer-term outcomes. However, children's outcomes are variable, with some children making substantial progress and others showing very slow gains. Although there is evidence that interventions lead to improvements, there does not appear to be a clear, direct relationship between any particular intervention and children's progress. Thus, while substantial evidence exists that treatments can reach short-term goals in many areas, gaps remain in addressing larger questions of the relationships between particular techniques and specific changes.

The committee recommends that ongoing measurement of treatment objectives and progress be documented frequently across a range of skill areas in order to determine whether a child is benefiting from a particular intervention and that the intervention be adjusted accordingly. Appropriate objectives should be observable, measurable behaviors and skills. These objectives should be able to be accomplished within a year and be anticipated to affect a child's participation in education, the community, and family life.

CHARACTERISTICS OF EFFECTIVE INTERVENTIONS

What are the characteristics of effective interventions in educational programs for young children with autistic spectrum disorders?

There is general agreement across comprehensive intervention programs about a number of features of effective programs. However, practical and, sometimes, ethical considerations have made well-controlled studies with random assignment (e.g., studies of treatments that systematically vary only one dimension) almost impossible to conduct. In several cases, features have been identified through correlational or comparative analyses and then assumed to be factors of importance in intervention programs, without further direct evaluation.

The consensus across programs is generally strong concerning the need for: early entry into an intervention program; active engagement in intensive instructional programming for the equivalent of a full school day, including services that may be offered in different sites, for a minimum of 5 days a week with full-year programming; use of planned teaching opportunities, organized around relatively brief periods of time for the youngest children (e.g., 15- to 20-minute intervals); and sufficient amounts of adult attention in one-to-one or very small group instruction to meet individualized goals. Overall, effective programs are more similar than different in terms of levels of organization, staffing, ongoing monitoring, and the use of certain techniques, such as discrete trials, incidental learning, and structured teaching periods. However, there are real differences in philosophy and practice that provide a range of alternatives for parents and school systems.

The committee recommends that educational services begin as soon as a child is suspected of having an autistic spectrum disorder. Those services should include a minimum of 25 hours a week, 12 months a year, in which the child is engaged in systematically planned, and developmentally appropriate educational activity toward identified objectives. What constitutes these hours, however, will vary according to a child's chronological age, developmental level, specific strengths and weaknesses, and family needs. Each child must receive sufficient individualized attention on a daily basis so that adequate implementation of objectives can be carried out effectively. The priorities of focus include functional spontaneous communication, social instruction delivered throughout the day in various settings, cognitive development and play skills, and proactive approaches to behavior problems. To the extent that it leads to the acquisition of children's educational goals, young children with an autistic spectrum disorder should receive specialized instruction in a setting in which ongoing interactions occur with typically developing children.

PUBLIC POLICIES

What public policies at the local, state, and federal level will best ensure that individual children with autistic spectrum disorders and their families have access to appropriate education?

The Individuals with Disabilities Education Act contains the necessary provisions for ensuring rights to appropriate education for children with autistic spectrum disorders. Yet the implementation and specification of these services are uncertain. The treatment of autistic spectrum disorders often involves many disciplines and agencies, which confuses lines of financial and intellectual responsibility and complicates assessment and educational planning. However, a number of states have successfully addressed some of these challenges and can provide model approaches for doing so.

The committee recommends that coordination across services and funding at federal and state levels should be encouraged through several mechanisms: the creation of a federal joint agency task-force on autistic spectrum disorders; state monitoring of coordination among service delivery systems; minimum standards for personnel in educational and early intervention settings for children with autistic spectrum disorders; and the availability of ombudspersons within school systems who are knowledgeable about autistic spectrum disorders and are independent of the school program. Coordinated, systematic strategies should be developed to fund the interventions that are necessary in local communities for children under age 3 years and in local schools so that this cost is not borne totally by parents or local school systems.

PERSONNEL PREPARATION

How should personnel who work with children with autistic spectrum disorders be prepared and trained to guarantee a sufficient number of well-qualified specialists and regular teachers and administrators?

The nature of autistic spectrum disorders and other disabilities that frequently occur with them has significant implications for approaches to education and intervention at schools, in homes, and in communities. Approaches that emphasize the use of specific one-size-fits-all packages of materials and methods may understate the multiple immediate and long-term needs of individual students for behavioral support and for instruction across areas. Teachers and other professionals and paraprofessionals who often provide the bulk of service to very young children need familiarity with the course of autistic spectrum disorders and the

range of possible outcomes and with the many methods that fit into best practices. Specific problems in generalization and maintenance of behaviors also affect the kind of training needed, as does the wide range of IQs and verbal skills associated with autistic spectrum disorders, from profound mental retardation and severe language impairments to high intelligence.

Multiple exposures, opportunities to practice, and active involvement are all important aspects of learning for teachers and other professionals. Technical assistance consisting of ongoing consultation, hands-on opportunities to practice skills, and building on the knowledge of teachers as they acquire experience with children with autistic spectrum disorders are crucial. Administrative attitudes and support are critical in improving schools, as are explicit strategies for keeping skilled personnel within the field. Providing knowledge about autistic spectrum disorders to special education and regular education administrators as well as to specialized providers with major roles in early intervention (e.g., speech language pathologists) are also critical in proactive change.

The committee recommends that the relevant state and federal agencies, including the Office of Special Education Programs, should accelerate their personnel preparation funds for 5 years for those who work with, and are responsible for, children with autistic spectrum disorders and their families. These efforts should be part of a larger effort to coordinate and collaborate with the already established infrastructure for special education, including regional resource centers and technical assistance programs.

RESEARCH

What research and further scientific investigations of effective education for young children with autistic spectrum disorders are needed?

A number of comprehensive programs report results on their effects, but interpretations of these results have been limited by several factors: practical and ethical difficulties in randomly assigning children and families to treatment groups; problems in selecting contrast groups; inadequate description of the children and families who participated in the studies; and lack of fidelity of treatment or generalization data. There is little evidence concerning the effectiveness of discipline-specific therapies, and there are no adequate comparisons of different comprehensive treatments. However, there is substantial research supporting the effectiveness of many specific therapeutic techniques and of comprehensive programs in contrast to less intense, nonspecific interventions. Research would yield

more valuable information if there were minimal standards in design and description of intervention projects.

The committee recommends that all intervention studies provide adequate information on the children and families who participated and those who chose not to participate or withdrew from participation, describe the intervention in sufficient detail so that an external group could replicate it, measure fidelity of treatment, and include objective measures of short-term and long-term outcomes that are assessed by independent examiners. The federal agencies involved in autism initiatives—including the Office of Special Education Programs, the Office of Educational Research and Improvement, the National Institute of Child Health and Human Development, the National Institute of Mental Health, the National Institute on Deafness and Other Communication Disorders, and the National Institute of Neurological Disorders and Stroke—should establish a joint task force and call for proposals for longitudinal and other intervention studies that assess the relative effectiveness of treatments and that investigate the effectiveness of different educational and treatment models for children, with individual differences defined either according to broadly delineated categories (e.g., children with autistic spectrum disorders with average or greater intelligence) or according to continuous dimensions (e.g., chronological age), and that consider the effects of selection or assignment. Competitively funded initiatives in early intervention in autistic spectrum disorders should routinely provide sufficient funding for short- and long-term assessment of program efficacy. Complementary research on the development of more specific, precise measures of outcome, educational skills, and sequences should be supported to assess the effects of interactions between family variables, child factors, and responses to interventions, and to identify the active ingredients and mediating variables that influence effects of treatment.

In summary, education at home, at school, and in community settings remains the primary treatment for young children with autistic spectrum disorders. Many specific techniques and several comprehensive programs have clear effects on important aspects of these children's learning. Yet links between interventions and improvements are also dependent on characteristics of the children and aspects of the treatments that are not yet fully understood. The challenges are to ensure implementation of what is already known so that every child benefits from this knowledge and to work from existing research to identify more effective educational interventions for all children with autistic spectrum disorders.

Educating Children with Autism
<http://www.nap.edu/catalog/10017.html>