

Finding Effective Intervention and Personnel Preparation Practices for Students With Autism Spectrum Disorders

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ABSTRACT: *The CEC Research Award recognizes researchers for the significant contributions they have made to special education. We believe that the members of this distinguished group have much to share with our readers. We have invited each of them to contribute an article, addressing their perspectives on special education research and practices. Richard Simpson was awarded the Research Award in 2002. This article by Simpson presents his motivations for entering the field and what he has learned from his work with children and youth with autism spectrum disorders; selected representative references are also provided.*

My path into our profession was circuitous in comparison to the trajectory of many of my colleagues who knew that they wanted to be special educators early in their careers or life. Indeed, as a high school and college student, I not only had no interest in teaching or working with individuals with disabilities, but I had little respect for educators' capacity or interest to serve students with special needs. Moreover, I had near contempt for mental health professionals. I generally perceived these individuals to be buffoonish, to possess little in the way of functional knowledge and skill, and to be far more likely to confuse or worsen a problem than to solve it. This negative preconception was in large measure forged by watching my older sister

struggle with her own mental illness. Both at home and at school, I witnessed first-hand the daily frustration of my sister and family caused by the actions and inactions of my public school. While I was a successful student in this same school, teachers and administrators not only failed to attempt to accommodate my sibling's special needs, but also seemingly took steps to purge her from the system.

I also observed the frustrations and endless efforts of my mother and father as they attempted to understand and advocate for my sister, including exploring and attempting what seemed at the time to be every imaginable alternative. It seemed that each new therapist and mental health team advocated for a novel approach or a slightly different twist to an otherwise basic treatment strategy. In some cases, these individuals were able to

bring solace to my family and some improvement, albeit typically short-term, for my sister. However, in all too many cases, these so-called "helping professionals" appeared to do more harm than good. One short-lived intervention, for instance, involved my parents being instructed to reflect the "pain" as well as the irrational and out-of-control behavior of my sister. Unfortunately, this was the extent of the treatment plan; that is, they were told to do nothing more than to reflect empathy and demonstrate unconditional acceptance in response to my sister's aberrant behavior. That my parents were repeatedly admonished by this particular mental health team to refrain from applying consequences for my sister's inappropriate behavior, no matter how bizarre or potentially dangerous, as had been previously recommended by other treatment teams, resulted in considerable chaos and confusion for all of us. In hindsight, I am sure my parents considered this particular approach, and other equally ineffective strategies, to lack logic or any other base that would produce desired outcomes. However, in the interests of their child and our family, and because doctors and other professionals were making these recommendations, they attempted each new method with optimistic resolve. Amazingly, my parents gave every appearance of being irrepressibly hopeful and unshaken during the tenure of each new purportedly effective strategy that was used. Yet, at the same time, the blame aimed at my parents from professionals for these system failures and my sister's deteriorating condition that inevitably followed application of the various ineffectual methods must have been unbearable.

My sister was poised in the unenviable position of having a unique perspective on her disability and the therapeutic approaches that were applied. Moreover, she was never shy about candidly sharing her opinion of her treatment. On one occasion, when I was in high school and my sister was at home for a weekend break from one of the many psychiatric hospitalizations that characterized her adolescence, we talked about her "therapies." To this day, I manifestly relive the guilt, anger, and resentment I experienced in response to my sister's description of the interventions to which she was subjected, including her tearful display of the circular-shaped tanned areas on her temples marking where electric shock ap-

paratus had been placed, her description of the memory and skill loss that followed shock therapy, visible bruises from alleged mistreatment, and other graphic reminders of what I could only judge at the time to be barbaric and ineffective treatment of an individual with a severe mental illness.

Readers may find this introduction to be self-promoting and self-serving. That is not the purpose, whatever the reaction. Indeed, I have steadfastly avoided sharing my personal experiences in a public forum and otherwise using my sister's disability to establish or advance my own professional credibility. Yet, it would be the height of self-deception to suggest that these experiences have not influenced my professional work. Accordingly, it is with considerable diffidence to my sister and family that I offer this information as background for my perspectives and attitude related to special education and the helping professions, and especially for my interest and work with students with autism spectrum disorders (ASD). Indeed, as sagely observed by Nia Vardalos in her role as the lead character in the movie *My Big Fat Greek Wedding*, we cannot separate ourselves and our respective identities from that of our family experiences. Accordingly, I humbly confess that my personal experiences have consciously and/or unconsciously had a bearing on my professional work and interests. In particular, my professional work has been characterized by improving practices in two areas that have traceable roots to my family experiences and professional training: (a) identification and correct application of scientifically based and other effective practices; and (b) preparation of high-quality, well-trained, and dedicated teachers and related service professionals for children and youth with disabilities.

THE AUTISM JOURNEY

In spite of my initial resistance and a lingering perception that educators and mental health professionals were often poorly equipped to craft and implement effective programs for students with disabilities, I nevertheless gravitated toward a career in special education. This process initially involved enrolling in education and psychology

courses, and ultimately claiming these disciplines as my major. Subsequent to completing undergraduate and master's degrees, I worked as a school psychologist and teacher of students with behavior disorders. And although obvious to those around me, I finally accepted that my professional life's work would be in the field of exceptional education.

I was fortunate to connect with several exemplary role models in the early stages of my career. These colleagues were both my trainers and my mentors, and were responsible for assisting me in gaining admission to a doctoral program. During my doctoral program, I had my first significant exposure to students who were diagnosed with autism. Ostensibly hired as a psychologist and support resource for a university-based demonstration program for special needs students, my contributions were, at best, modest. My experienced and skilled colleagues were appreciative of my youthful energy and willingness to assist with less desirable and mundane student-related tasks while simultaneously showing tolerance for my naive and unpracticed professional skills. I am very confident that I offered little in the way of legitimate professional-level support or technical assistance to the teachers and staff. In contrast, the students, teachers, and related services staff taught me more than I could possibly describe.

Moreover, I took great delight in observing the positive outcomes that accrued when a well-trained multidisciplinary staff used effective practice methods in a coordinated fashion, particularly when these methods were individually orchestrated in accordance with family needs, preferences, and resources.

I was both fascinated and spellbound by these children with autism. Moreover, I took great delight in observing the positive outcomes that accrued when a well-trained multidisciplinary staff used effective practice methods in a coordi-

nated fashion, particularly when these methods were individually orchestrated in accordance with family needs, preferences, and resources.

My interest in autism was given a significant jumpstart when I received federal funding for a large-scale ASD demonstration and research project early in my career. The Severe Personal Adjustment (SPA) Project operated from 1975-1978 in partnership with the Kansas City, Kansas, public schools. Funding for the SPA project, which occurred at approximately the same time as the passage of the original Education for All Handicapped Children Act, was provided as a means of demonstrating and supporting research related to serving children and youth who had previously been considered to be too severely impaired to attend public schools. The Kansas City, Kansas, schools contributed public school classroom and office space along with 12 of the most challenging children and adolescents anyone in our community had ever seen. Over the next 3 years, my colleagues and I learned a great deal about educating children and youth with autism. Indeed, some of my most energizing and rewarding professional experiences occurred during this period. Subsequent projects and experiences, including "tours of duty" as principal of a preschool for children with autism and a campus-based demonstration school for students with autism, increased even further my interest in students with ASD. I was also fortunate in finding a sympathetic ear for the notion that there were insufficient publication outlets to permit timely dissemination of practitioner-oriented information and research related to serving individuals with ASD to educational professionals and parents. Discussion of this issue resulted in creation of *Focus on Autistic Behavior*, a publication that later became *Focus on Autism and Other Developmental Disabilities*.

During the course of first entering the profession to the present, there has been momentous change in the field of autism. Indeed, autism has moved from being a relatively unrecognized disability to having a position of notoriety. Furthermore, children and youth identified with autism today are more diverse than those with the disability 30 years ago. While unique related to their individual personalities and distinctive human traits, the students with autism of the 1970s were

more homogeneous in intellectual, language, and behavioral characteristics than are students with ASD today. That is, these now adult-aged students with autism more consistently displayed similar patterns of severe intellectual deficit, absence of spoken language, self-injurious behavior, social isolation, severe aberrant behavior, and so forth, than did students with Asperger's syndrome, higher functioning autistic disorder, Rett syndrome, and other forms of autism that form the spectrum of today. Accordingly, the challenges of serving children and youth with ASD today are greater than what I experienced in the early stages of my professional career relative to the demands associated with assessing and responding to the needs of a more diverse group within myriad settings.

Autism can no longer be considered a low-incidence disability; the condition occurs with far greater frequency than ever considered imaginable! At the same time, however, it is obvious that autism is not a "new" condition, but rather one that professionals and parents have recognized over the course of history, including before the time that Leo Kanner (1943) stamped the disability with its name. Nevertheless, it is unequivocal that individuals are being diagnosed with ASD far more frequently than at any time in history. That only a few decades ago there were thought to be a mere handful of these students, however, made the condition less of a challenge than it is today. In no way is this a suggestion that families of children and adolescents diagnosed with autism in the past had an easier time in meeting the needs of their family member with a disability than do families today. That is clearly not the case. However, the significant recent increase in the prevalence of ASD makes this disability a daunting challenge for schools and communities worldwide relative to developing an infrastructure to serve a far greater number of individuals. Indeed, autism is such a frequently encountered developmental disorder that some states have reported it to be of epidemic proportion (Feinberg & Vacca, 2000).

In this connection, my early experiences in the field of autism occurred in a restrictive and highly specialized setting staffed by individuals with unique and uncommon skills and knowl-

edge. That there were thought to be few individuals with autism, and that these individuals were generally perceived to be unsuited for public school participation, made professionals who chose to specialize in autism a relatively small group. Moreover, these professionals were predominately considered to possess such specialized and esoteric skills and knowledge that there was limited need for their services in most schools and communities. The current demand for personnel with autism-related skills is clear evidence that this perception has changed!

In spite of the extraordinary recent media coverage and other attention that autism has received, it continues to have the same mystique that it had when I first entered the field. That is, in spite of significant advancements in treating and understanding individuals with ASD, the disability remains a mystery. Even when viewed through a disability lens, individuals with ASD are a particularly challenging and enigmatic group. Their highly unique characteristics and multiple disabilities have fueled debates over the cause of the disorder as well as preferred educational programming and intervention choices. This phenomenon has not changed over the course of the time I have worked with students with ASD; in fact, it has intensified. Related to this uniqueness, autism is perceived by many professionals and parents to be such a singular disability that its uniqueness requires separate and distinctive specialized intervention methods, curricula, and programs. In this connection, autism has a strong legacy of controversy related to both effective treatments and interventions and to effective preparation of personnel qualified to teach and otherwise work with students with ASD.

Of course, the interventions and treatments have varied dramatically over the course of history, including during the time I have been in the field. When I first entered the profession, there were remnants of psychodynamic and other interventions based on bonding and forming interpersonal relationships being used in a number of clinical settings with students with ASD. Based on the notion that autism was an emotional reaction to environmental factors, most notably an absence of maternal warmth and caring (Bettelheim, 1967; Kanner, 1949), there were some pro-

professionals who preferred and used treatments such as psychoanalysis and nondirective play therapy. However, these methods were being largely discredited and their efficacy was clearly questionable. The preferred and emerging method was applied behavior analysis (Bijou & Baer, 1961; Lovaas, 1969), albeit it was being used in a less positive and sophisticated fashion than today. Moreover, pharmacological and other physiologically based interventions were emerging, and their potential as elements of an effective comprehensive treatment program was just beginning to be understood. Yet, in spite of the significant changes in intervention options and treatments for persons with ASD that have occurred over the past several decades, there has been a consistent lack of agreement related to the efficacy of these methods. Furthermore, there has been a paucity of professionals who are trained to use effective methods with students with ASD.

EFFECTIVE INTERVENTIONS FOR STUDENTS WITH ASD

To acknowledge that there is debate over which interventions for children and youth with ASD are most effective would be a significant understatement. There is significant and often strident disagreement as to what constitutes an appropriate program for children and youth with an autism-related diagnosis. Moreover, the ASD field is particularly well known for its willingness to embrace and/or maintain a liberal tolerance toward unproven and controversial interventions and treatments. A number of these purportedly effective methods appear to have neither empirical nor logical foundation. Furthermore, the majority of the interventions and treatments commonly used with students with ASD have not been thoroughly evaluated; and, even scientifically supported strategies such as applied behavior analysis are involved in debates related to anticipated outcomes and procedural issues such as extensive and exclusive use. That the list of intervention and treatment options for individuals with ASD is rapidly expanding has further intensified the problem of professionals' and parents' abilities to agree on the most effective strategies for individual students. Testimony for

this significant problem includes the inordinate number of methodology-focused due process and mediation hearings involving students with ASD. The equation of a highly diverse and misunderstood disability in combination with the aforementioned large number of well-hyped intervention choices, a number of which appear to lack utility, serves as at least a partial explanation for the treatment and intervention controversy in the ASD arena. Of course, other disability areas face the same issues; however, for whatever reason, the autism area has greatly exceeded others in both frequency and intensity related to this controversy.

Based on my experiences and interpretation of the literature, it appears that there is no single, universally best suited and effective method for students with ASD.

Based on my experiences and interpretation of the literature, it appears that there is no single, universally best suited and effective method for students with ASD. Increasingly, it is clear that the best programs are those that incorporate a variety of multidisciplinary best practices based on individual needs. A number of these methods have been identified; hence, there is now a foundation core available to support basic effective practices for students with autism-related disabilities. Although beyond the scope of this article, these options include a variety of strategies designed to enhance skills in areas of deficit (e.g., Picture Exchange Communication System, applied behavior analysis, structured teaching), environmental supports and modifications (e.g., visual supports, routine), and biologically based interventions and treatments (e.g., psychopharmacologic treatments). Unfortunately, these foundation elements are often absent from many school and community programs.

Individuals with diagnoses that fall on the autism spectrum continue to have among the poorest of prognoses compared to other groups with disabilities, and they frequently demonstrate poor responses to intervention efforts. Hence, al-

though there is a clear need for identification and use of effective methods, it is also important that the mantra of "effective practice" not be used to impede the development of novel efficacious treatments and interventions. Support for development and evaluation of new approaches to better serve students with ASD continues to be a significant need. At the same time, it is essential that there be an ongoing evaluation of purported interventions and treatments, and that the field identify unproven strategies as experimental until such time as they have demonstrated their worth.

Both parents and professionals can be expected to consider using various unproven interventions and treatments. Nowhere has this pursuit been more vigorous than with persons with ASD. Indeed, one of the most well-defined characteristics of programs and interventions for students with ASD has been the never-ending search for factors or strategies, proven or not, that purportedly restore an individual with autism to normalcy, or that significantly advance the development of skills, knowledge, and overall progress beyond that typically found with established effective practice methods. Of course, who would expect parents and professionals to not consider approaches that might promise to reclaim children to a typical state!

Yet, overreliance on unvalidated methods, especially those that promise extraordinary results, has had an overall negative influence on the field. Casual and uncritical approval of undocumented, highly touted interventions and treatments that promise miracles has diverted attention away from the need for a program foundation based on proven methods. Programs for students with ASD that have adopted and overly relied on short-lived miracle cures and unproven methods have slowed students' progress and fostered the creation of unrealistic and inconsistent expectations. Additionally, overreliance on undocumented interventions and treatments has complicated the process of discriminating innovative procedures that have promise for effective professional application from those whose primary strength is hyperbole and exaggeration. There is no question that our field desperately needs renewed and revived optimism and hope. Yet, related to methodology choices for persons with autism, optimism and hope best thrive and support families and profes-

sionals when they are tied to interventions and treatments that have proven worth, and when experimental intervention and treatment approaches are based on sound theoretical and empirically valid assumptions and models.

PREPARING QUALIFIED PERSONNEL FOR STUDENTS WITH ASD

There is overwhelming evidence that there is a shortage of teachers and other professionals who are qualified to serve the needs of students with disabilities, and there is every reason to believe that this trend will continue for at least the short term. The shortage of qualified professionals to educate children and youth with special needs, including those with ASD, is the most significant challenge facing the field. In the case of students with ASD, personnel require a foundation of basic general and special education skills along with specialty skills in the area of autism, including an understanding of their characteristics; and skill and knowledge in assessment, diagnosis, and evaluation. Teachers of students with ASD also need skills in curricula and instructional methods unique to ASD, including (a) social interaction, communication, and independent-living enhancement strategies; (b) sensory support and accommodation strategies; (c) environmental management and accommodation methods; and (d) positive behavioral interventions. These instructional and management methods must be explicitly taught, and these skills must be modeled and practiced in field placements with students with ASD. Related to the training of personnel specifically for children and youth with ASD, this recommended training model often juxtaposes poorly and directly conflicts with trends toward noncategorical and cross-categorical teacher training and generic teacher licensure.

A weakened economy along with tepid political support for education makes the prospect of a significant increase in the availability of well-trained teachers and related services professionals to educate students with ASD, at least in the near future, highly unlikely. Historically and even today, few well-designed and specialty-focused preservice programs to prepare teachers of stu-

dents with ASD are available. Further, inservice training programs designed to build knowledge and skills in individuals who work with students with ASD are often insufficient in number and limited in scope and content. These challenges, of course, come at a time of rapid growth in the prevalence of children who have been identified with ASD. Given the trend of preparing special education generalists and the limited availability of autism training opportunities, it is unrealistic to expect that the majority of teachers and staffs who work with a student with an ASD will have completed a comprehensive preservice program specifically in the area of autism. However, it is reasonable and realistic to expect that these professionals will be well-trained special educators, general educators, and related services professionals who will have completed a professional training program wherein they have acquired knowledge, skills, and experiences suitable for allowing them to teach and manage students with ASD effectively. Thus, even when ASD is not an exclusive area of training, it nonetheless should be included as a significant part of the training process for professionals who have responsibility for students with an autism-related disability. We are far from achieving this goal; however, to permit professionals who serve students with ASD to teach without appropriate training bodes so poorly for the profession that there are few alternatives but to set such a standard. Personnel training must also extend to children and youth with ASD who are assigned to general education classrooms. Diagnostic groups such as children with Asperger's syndrome are primarily educated in general education classrooms. Hence, teacher education curricula and experiences must be designed to prepare general educators and administrators to work with students with ASD in general education classrooms as well as engage in collaborative and cooperative activities with special educators, educational related services, community service providers, and parents.

WHAT I KNOW ABOUT ASD (A.K.A. WHAT I "FOUND")

Careers in special education typically afford few opportunities to write articles such as this. Con-

sidering readers' needs and tolerance for cathartic reflections, this is not an altogether unfortunate fact. Nevertheless, I decided to use the invitation to write this article as an opportunity to undertake a personal examination of what I have learned over the course of my career, why I have certain strongly held beliefs, and why I have promoted certain practices.

These reflections have led me to conclude that there is a clear and dramatic need for the identification and correct application of effective methods and strategies for children and youth diagnosed with ASD.

These reflections have led me to conclude that there is a clear and dramatic need for the identification and correct application of effective methods and strategies for children and youth who have been diagnosed with ASD. It has been my experience that these students can be expected to respond most positively when teams of professionals, parents, and advocates are permitted to incorporate a variety of current best practices into comprehensive, individualized programs, and when they are permitted to prudently weave promising experimental approaches into the fabric of these programs. Equally important is the need for well-trained and dedicated professionals who possess the skill, knowledge, and experiences to implement and evaluate these interventions and treatments effectively. Considering the progress that has been made with students with ASD, there is much to applaud. Yet, applause of any type at this point would be inappropriate, given the magnitude of what must yet be done to meet the myriad needs of children and youth with ASD and their families.

My autism-related experiences have primarily resulted in written products in four primary areas: (a) effective classroom practices, (b) personnel preparation, (c) parent/family support, and (d) distinguishing traits and unique features of individuals with ASD. Related to these four areas are selected journal articles and books (listed below) spanning my time in the field.

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DEPARTMENT OF SPECIAL EDUCATION

The Department of Special Education announces six tenure track assistant professor positions available in August 2004. Responsibilities in each position include teaching undergraduate and graduate courses, advising, supervision of student teachers and/or practicum students, conducting scholarly and service activities, and working collaboratively in a field-based training program. Qualifications for each position include a Master's Degree plus eighteen (18) hours, earned doctorate preferred.

F0438: ASSESSMENT IN SPECIAL EDUCATION

For additional responsibilities and qualifications, please see: <http://www.emich.edu/public/aa/ahr/F0438.htm>

F0439 ASSISTIVE TECHNOLOGY IN SPECIAL EDUCATION

For additional responsibilities and qualifications, please see: <http://www.emich.edu/public/aa/ahr/F0439.htm>

F0440: COGNITIVE IMPAIRMENT (MENTAL RETARDATION)

For additional responsibilities and qualifications, please see: <http://www.emich.edu/public/aa/ahr/F0440.htm>

F0441 EMOTIONAL IMPAIRMENT/BEHAVIOR DISORDERS

For additional responsibilities and qualifications, please see: <http://www.emich.edu/public/aa/ahr/F0441.htm>

F0442 HEARING IMPAIRMENT/SPEECH-LANGUAGE IMPAIRMENT

For additional responsibilities and qualifications, please see: <http://www.emich.edu/public/aa/ahr/F0442.htm>

F0443 LEARNING DISABILITIES

For additional responsibilities and qualifications, please see: <http://www.emich.edu/public/aa/ahr/F0443.htm>

Review of applications will begin December 1, 2003, and continue until the position is filled. Send application, resume, transcripts and three (3) current letters of recommendation to: **Posting #, Eastern Michigan University, 202 Boone Hall, Ypsilanti, MI 48197.**

Women and members of minority groups are encouraged to apply. EMU is an affirmative action/equal opportunity employer committed to faculty, staff and student diversity.

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