Patients with autism spectrum disorders (ASDs) can present with extremely heterogeneous issues, and, therefore, their treatment can be very challenging. Most patients with ASDs will benefit from contact with a multitude of disciplines. In this article, treatment planning is structured in terms of the patient’s life stages. Early on, assessment of developmental milestones, metabolic conditions, and hearing; making the diagnosis of ASD; and providing genetic counseling are salient. As the child grows, speech and language therapy, early intensive intervention, special education, parent training, and neurologic assessment become important. With greater age, behavior therapy, pharmacotherapy, occupational therapy, and sexuality issues are often in ascendancy. As the patient approaches and proceeds through adulthood, transition training, housing options, and guardianship issues may be priorities. Advocacy is relevant throughout the life span. Professionals have an obligation to familiarize parents with interventions likely to be fruitful or unhelpful. There is growing evidence that early intensive behavior intervention, though expensive, may produce lifelong gains in functioning. A variety of experimental and/or unproven treatments are identified; mental health professionals can help families with members who have ASDs by guiding them toward effective treatments and away from therapies of unknown value but with potential risks and/or costs.

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Where does the interested professional go to acquire skills in treatment planning for patients with ASDs? I hope that this article goes some distance in helping to achieve this. Excellent sources of information are the “practice parameters” for the assessment and treatment of ASDs that were published by the American Academy of Child and Adolescent Psychiatry, the American Academy of Pediatrics, and the American Academy of Neurology, and a consensus panel also associated with these bodies.19

ELEMENTS OF CARE REQUIRING MANAGEMENT

Individuals with ASDs often require a multitude of resources to be brought to bear during their lifetimes. Some aspects are as follows. First, individuals with autism and PDD-NOS often present with intellectual and educational handicaps as well. Therefore, these individuals will require the best forms of educational training that we can provide. Second, almost by definition, patients with autism usually present with communication handicaps, and they will usually require some form of speech and language therapy. There is a multitude of other skills and techniques these individuals can be taught as well, such as the Picture Exchange Communication System, peer-mediated intervention, social stories, and pivotal response training. Children with ASDs often present with coordination and/or motor deficits, for which they may require occupational therapy, physical therapy, or adaptive physical education. Patients with ASDs frequently have behavioral excesses and/or comorbid psychiatric conditions. As a result, they may benefit from applied behavior analysis (ABA) and pharmacotherapy. Many families seek out complementary and alternative medical (CAM) treatments both for behavioral and psychiatric issues and for core ASD symptoms. Finally, the parents of children with ASDs often experience significant stress trying to deal with all of the challenges presented by their sons and daughters. In a recent statewide survey of families with children with an ASD, Lecavalier et al. found that 58% of mothers reported stress scores in the clinical range. Parents may require relief in the forms of community support, parent training, and respite care.

STATUTES AFFECTING INDIVIDUALS WITH ASDs

It is important for all therapeutic partners to realize that patients with ASDs share certain important rights that should have a positive impact on their education and their later access to employment. The relevant legislation began with Public Law 94-142, enacted in 1975.19 This law was amended several times and is now known as the Individuals with Disabilities Education Act (IDEA) or Public Law 105-17 (reauthorized in 1997 and 2004).19 Autism is specifically identified as a condition covered in the provisions of IDEA. IDEA logically captures most patients with PDD-NOS and Asperger’s syndrome as well, as the following disability categories are written into the law: (1) physical, (2) cognitive, (3) communicative, (4) social, (5) emotional, and (6) adaptive development. Services covered include early identification and assessment, transportation, speech-language pathology, audiology, psychology, counseling, physical and occupational therapy, medical services for diagnosis or evaluation, social work in school, assistive technology, adapted physical education, and parent training and counseling.19,20 IDEA also requires that transition services be included as well to prepare students for post-school activities. Services include vocational assessment, vocational training, supported employment, preparation for independent or supported living, and liaison between schools and agencies that provide support to adults with disabilities.19

Initially, IDEA addressed needs for young people aged 3 to 21 years, inclusive. In 1986, amendments were added to IDEA to address the needs of infants and toddlers under 3 years of age (Public Law 99-457). This law requires states to have statewide systems for identifying children with developmental delays, to coordinate referrals, and to provide evaluations and services for such children and their families.19,20 According to Berkman, services provided by IDEA are not mandatory outside the 5- to 18-year age range “to the extent that such a requirement would be inconsistent with state law.” Certain states (e.g., Arizona) will provide supplemental insurance coverage (through the Division of Developmental Disabilities) for children with the diagnosis of autism, but will not provide coverage for PDD-NOS or Asperger’s syndrome because those diagnoses are not specified in state law (personal communication, Ronald Lindsay, M.D.). In addition to these education-based statutes, there are other laws relevant to patients with ASDs. These include Section 504 of the Rehabilitation Act and the Americans with Disabilities Act (PL 101-336), which are intended to protect against discrimination due to a disability. The important message to be gleaned from all of this is that there is significant legislation to protect the rights of patients with ASDs and to assist in their education. If at least 1 member of the therapeutic team is aware of these provisions, advocacy efforts are much more likely to be successful.

CONCEPTUALIZING TREATMENT PLANNING—A LIFE-STAGE APPROACH

It is clear at this point that patients with ASDs present with a wide range of needs; these are likely to change as the individual ages and goes through the life cycle. Table 1 presents a schema for conceptualizing the planning process. Some examples follow.

At the time of birth, a variety of metabolic screens may take place, and it is possible, for example, that phenylketonuria, caused by a deficiency of phenylalanine
hydroxylase, may be revealed. In this case, a diet mostly free of phenylalanine (an essential amino acid) would be prescribed and ASD might be averted in a vulnerable child. A suspicion of autism, ASD, or mental retardation should prompt consideration of additional metabolic testing including urine for organic acids and blood for amino acids. Other metabolic defects said to be associated with autism, generally not covered by routine newborn screening tests, include histidinemia, adenylosuccinate lyase deficiency, dihydropyrimidine dehydrogenase deficiency, 5'-nucleotidase superactivity, and phosphoribosylpyrophosphate synthetase deficiency. A lead level should be obtained for children with a prolonged history of pica or high environmental risk. Genetic testing should also be considered for children newly diagnosed with ASDs. Clinical criteria for disorders such as fragile X syndrome are not an adequate substitute for genetic testing. Testing should include DNA testing for fragile X syndrome, high-resolution chromosome testing, and fluorescent in situ hybridization testing for Williams syndrome and subtelomeric deletions. The following are not recommended: functional magnetic resonance imaging (fMRI), allergy testing, hair analysis, chelation challenge testing, gut permeability studies, and stool analysis.

Likewise, a family history of ASD would trigger a high level of vigilance, from the time of birth onward, for signs and symptoms of autism. Some infants and toddlers (some of whom will go on to develop ASDs) appear not to respond to normal sound stimuli. This might well trigger a referral to an audiologist for appropriate assessment, such as by frequency-specific auditory brainstem response, the single most useful electrophysiologic audiometry assessment procedure in infants and young children. Infancy and toddlerhood are times when parents, pediatricians, nurses, and others should closely monitor developmental milestones. Likewise, care providers and parents should be alert at this time for early signs of social interaction, such as the child’s responding to his or her name, joint attention, babbling, single words, pretend play, and imitation. Failure of these to emerge in a timely fashion or the loss of language or social skills at any time should trigger—at the very minimum—a screen for ASD. Many psychiatrists first come into contact with the individual with ASD when the parents seek a formal diagnosis. From this point onward, the psychiatrist can become an important member of the treatment team. He or she can help to ensure that the patient receives the various supports described here and in Table 1. Early childhood and adolescence are periods of increased risk for onset of seizures, although epilepsy may first appear at any time in the life of patients with ASDs.

Advocacy is an activity that should be in force throughout the lifetime once an ASD has been diagnosed. However, the needs for advocacy are likely to be greater at certain times, such as prior to school entry, early in the school career, and at times of transition, such as when the individual is seeking employment or housing. A good knowledge of the relevant statutes is likely to make such advocacy more fruitful. Another form of advocacy involves the selection and/or promotion of appropriate therapies. Professionals can fulfill this role by helping to steer families toward effective treatments at appropriate times and away from proven or bogus treatments that can be expensive in both time and money.

As communication and language impairments so frequently accompany the ASDs, it is imperative that individuals receive speech and language therapy to address the array of communication, pragmatic (the social use of language), and oral and written language impairments with which these children may present. Such therapy is especially likely to occur during toddlerhood, preschool, and

| Life Stage     | Birth ++ | Infancy +++ + + ++ ++ + | Toddlerhood +++ ++ ++ +++ ++ ++ ++ | Preschool ++ +++ + ++ +++ +++ ++ + | Primary school +++ + + ++ ++ ++ ++ ++ | Adulthood +++ ++ ++ ++ ++ ++ ++ | Young adulthood ++ + ++ + ++ ++ ++ | Later adulthood ++ ++ ++ ++ ++ ++ ++ |

*Seizures most likely to start in infancy and adolescence.
Symbol: + = activity is in ascendency at this stage; ++ and +++ indicate increasingly greater levels of ascendency. The activity may be indicated throughout the life span.
primary school. These children may benefit from a multitude of interventions, such as the Picture Exchange Communication System, augmentative alternative communication (the range of assistive communication devices), and pivotal response training (e.g., play, initiating interactions).

Autism clearly has an important genetic component, and parents have a right to know, if they have one child with an ASD, that the odds of a subsequent pregnancy resulting in an offspring with an ASD are greatly increased. The Committee on Children with Disabilities reported that once a family has a child with an ASD, the risk of recurrence of ASD in subsequent children rises to 3% to 7%. The Quality Standards Subcommittee reported a 60% concordance rate for autistic disorder and 71% concordance for ASD in monozygotic twins. Therefore, genetic counseling should be attempted soon after the diagnosis of ASD is made. According to DSM-IV, 75% of children with autistic disorder also function in the range of mental retardation; a higher-than-usual rate can also be expected for PDD-NOS. Furthermore, many of these children have a variety of behavior problems or disorders (e.g., compulsions, stereotypies, rituals) that interfere with efficient learning. Therefore, most children with ASDs will require special education.

The Academies of Pediatrics, Neurology and Child and Adolescent Psychiatry practice parameters all gave at least moderate support to the position that children with autism receive intensive early intervention. This is usually characterized by an extensive step-by-step curriculum that targets language, daily living, and social skills of the children, usually for 25 or more hours per week, and employs ABA principles. Some professionals question the value of intensive early intervention on the grounds that it is too expensive or that it is ineffective. The issue of expense can be countered in 2 ways. First, it is often possible to cover much of the expense by chaining together federal funds from early intervention programs, Maternal and Child Health, Medicaid, special education, and local resources to alleviate some of the fiscal pressure on a given family. Second, if intensive early intervention programs are truly effective in reversing the course of ASDs, then this will alleviate financial pressure on the child’s family later in his or her life.

In terms of effectiveness, the available evidence is positive but incomplete. The American Academy of Neurology practice parameters cited 5 positive studies of intensive early intervention. The Surgeon General’s Report on Mental Health also acknowledged the importance of ABA and/or center-based early intensive intervention for these children. The Committee on Educational Interventions for Children With Autism assembled by the National Academies concluded that “available research strongly suggests that a substantial subset of children with autistic spectrum disorders are able to make marked progress during the period that they receive intensive early intervention, and nearly all children with autistic spectrum disorders appear to show some benefit.” However, this report also noted that there remains a need for well-controlled trials of intensive early intervention. This would appear to be a situation in which an error of omission (recommending intensive intervention) is less serious than an error of omission (remaining neutral or discouraging use of intensive intervention). Many practitioners of intensive behavioral intervention believe that there is a critical stage in the time before and leading up to primary school to achieve these gains in adaptive behavior, cognition, and social skills, and it may be difficult to justify not obtaining whatever level of intensive early intervention can be mounted by the community and family. Ordinarily, intensive early intervention would be commenced shortly after diagnosis and continued up to kindergarten or primary school, depending upon the child’s progress and areas of handicap.

It is important that professionals know what elements make for effective early intervention. According to Kabot et al., there are at least 6 important components, which include the following: (1) provision at the earliest possible age; (2) intensity (at least 20 hours per week); (3) parent involvement, training, and support; (4) curricula focused on social and communication functioning; (5) systematic instruction with individual goals; and (6) attention to generalization so that acquired skills are employed in all major settings. Obviously, the decision to employ intensive early intervention is not a light matter, but successful implementation may well make a major difference in the life of the child with the ASD and that of his or her family.

Most parents benefit from periodic training aimed at skills building and reduction of problematic behavior. Given the handicaps that children with ASDs usually experience, as well as their challenging behaviors, these parents will typically require training at key points, such as in toddlerhood and preschool (e.g., building skills in activities of daily living and communication; management of sleep problems). Parents are likely to benefit from training during adolescence as well, as the young person deals with emerging sexuality, newfound independence, larger body size (hence greater potential for damage in the context of disruptive behavior), and perhaps emerging forms of psychiatric comorbidity. Marcus et al. identified psychoeducation and behavior modification as the most common forms of parent training, but relation enhancement and cognitive approaches were also recommended. The National Institute of Mental Health Autism Research Units on Pediatric Psychopharmacology are currently testing a manualized parent management training package as adjunct treatment with medication in families with 4- to 13-year-old children (C. Johnson, Ph.D.; B. Handen, Ph.D.; E. Butter, Ph.D.; et al., manuscript sub-
mitten, 2005). This package emphasizes the management of behavioral excesses initially and the building of skills thereafter, with the parent as the agent of change.

Both behavior therapy and pharmacotherapy become increasingly salient as the person with ASD grows older; however, in the case of behavior therapy, it may become difficult to control the relevant contingencies in the context of behavior modification as the individual enters early and late adulthood. Medication surveys indicate very strong relationships between age and increasing use of psychotropic medicine in patients with ASDs. This probably reflects a complex interplay of maturity (leading to “adult” comorbidities), greater size (and, hence, potential for disruptive behaviors to have significant clinical impact), and higher expectations with greater age. As young people with ASDs mature, they need to acquire a multitude of practical skills ranging from cutting with scissors and printing/cursive writing to job-related skills and managing within their living space. This is part the domain of the occupational therapist, who is often best equipped to help in developing a command of these skills.

The sexuality issues that may be relevant to ASDs include masturbation, inappropriate touching, privacy issues, exploitation by others, and public display (exposure). Another concern often voiced by parents of younger individuals with ASDs is that these children are very poor at discriminating responsible and familiar adults from total strangers who may merely appear to be friendly. Obviously, this is an area in which the children may be at high risk. Transition training becomes important whenever the patient must make a major adaptation to a new setting or new routine (or both). This training becomes especially important as the individual matures and contemplates movement into a new home and/or workplace. The Ohio Task Force on Autism provides three simple principles for successful transition planning: (1) start early, (2) involve all service agencies and funding agencies, and (3) try to have work secured before graduation or identify postsecondary education options before graduation actually occurs. Marcus et al. noted that relatively little has been written about the planning needs of adults with ASDs. Some of the key issues include housing or residential care, job training and placement, social skills training, and estate planning. Employment options for adults with ASDs include sheltered workshops (most restrictive), secure employment, supported employment, and full independence. Predictors of successful employment include (1) employment readiness, (2) adequacy of job match, (3) higher degree of social competence by the individual concerned, and (4) provision and success of behavior management. Naturally, these predictors point to specific actions that mental health professionals can take to help adults with ASDs make their way in residential settings and the workplace.

Therapeutic Alliance

To be effective clinicians in managing ASDs, we need to form a therapeutic alliance with each family. This entails several aspects such as (1) respecting parents’ views; (2) advising the family on treatments with and without supporting evidence; (3) some flexibility toward CAM treatments; and (4) for families choosing CAM treatment, joining with the family to determine if the treatment is helpful (i.e., gathering clinical outcome data); (5) willingness to advocate for the family as it attempts to access needed services; and (6) willingness to work within a professional network. Maintaining a therapeutic alliance does not entail any of the following: (1) passive acceptance of anything proposed by the family, regardless of merit; (2) dictating treatments to the family; (3) lack of a data-based approach to treatments; or (4) outright rejection of CAM treatments. To be influential advocates, psychiatrists and other mental health professionals should have an awareness of some treatments that are questionable or that have been shown not to work.

Ineffective or Unproven Treatments

Space does not allow a review of the many treatments that have been advocated for treatment of autism or associated behavior problems. Therefore, I simply provide references to relevant reviews and provide the conclusions reached.

Facilitated communication. Facilitated communication (FC) was promoted on the basis of the notion that autism is a problem of expression rather than one of language. The idea was that the information was trapped within the individual without the intervention of a passive facilitator, who helps the individual tap out messages via keyboards. Despite the implausibility of the idea, it was enthusiastically embraced by many professionals and families alike. Dozens of studies of FC have been carried out, and the literature has been thoroughly and carefully reviewed by a number of scientists. These reviews have revealed that most research, especially well-controlled research, is overwhelmingly negative. Mostert found that the most poorly controlled studies often found FC to be effective, whereas the much larger body of well-controlled studies found little to no support.

Secretin. A medicine for diagnosing certain gastrointestinal conditions, secretin burst onto the clinical scene after a television Dateline documentary in which the mother of a boy with autism reported very dramatic improvements in autism symptomatology that followed diagnostic testing with secretin. Extensive media attention and widespread discussion and anecdotes on the Internet followed, and a very large number of families sought treatment for their children with ASDs. Secretin became a once-
in-a-generation phenomenon that seemed to hold great public health significance for many families and professionals alike.17 We are aware of 17 secretrin studies to date, 16 of which have been published. More than 500 children with ASDs have been involved in these investigations.17 None of these trials has reported a straightforward main effect of secretrin on autism symptoms, cognition, or problem behavior.38,39 A few trials have reported a significant effect in various subgroups (e.g., subjects with certain gastrointestinal problems, younger children), but none of these “special” effects has been replicated.38,39 Secretrin infusions are expensive and cannot be justified for other than gastrointestinal diagnostic purposes at this time.

Auditory integration training. Many individuals with ASDs display abnormal responses to stimuli (e.g., use of hands to cover ears), causing some workers (e.g., Berard; see below) to speculate that these patients suffer from auditory hypersensitivity.40 Sinha et al.40 and Baranek4 have provided excellent descriptions of types of auditory integration training (AIT) and their histories. Sinha et al.40 were affiliated with the Cochrane Database of Systematic Reviews, an agency that conducts systematic data-based meta-analyses of controversial treatments. The most popular form of AIT was developed by a French worker, G. Berard.4,40 AIT involves the identification of sound frequencies to which the patient is hypersensitive. Music is subsequently delivered by headphones to the patient, and filtering is used to dampen frequencies to which the individual is hypersensitive. The usual course of treatment involves at least 10 days of treatment with modulated music presented in 2 half-hour sessions per day.4,40 AIT is expensive, with fees ranging from $1000 to $3000.4 Another form of AIT is the Tomatis method, which employs delivery of electronically altered music and human voice for 150 to 200 hours over a period of 6 to 12 months.40 Both approaches claim improvements in hearing, autism symptoms, and problem behavior. Both Sinha et al.40 and Baranek4 have extensively reviewed existing research on AIT in autism. Both reviews found a lack of support for AIT effects in any therapeutic domain. Sinha et al. concluded that “AIT continues to be practiced worldwide . . . despite evidence which still shows it to be an experimental treatment at best, and which may only be available at a considerable financial cost to the family.”

B6 and magnesium treatment. For decades now, there have been case reports, surveys, and a variety of “clinical trials” that have claimed benefits in children with autism who were treated with megadoses of vitamin B6 (pyridoxine) alone or in combination with magnesium.41,42 These reports have claimed improvements in symptoms of autism and in disruptive behavior. Although there is a scattered literature claiming beneficial effects of B6 (plus or minus magnesium), reviews of this work generally suggest that it does not meet the usual standards of well-designed randomized clinical trials.41,42 Furthermore, pyridoxine can have adverse physical effects; these have been reported in a large trial in children with Down syndrome (photosensitive blisters, gastrointestinal symptoms, motor and sensory neuropathy).43 The most recent 10-week double-blind, placebo-controlled, crossover trial of B6 and magnesium failed to find any therapeutic effects.44 Nye and Brice,44 affiliated with the Cochrane Database of Systematic Reviews, evaluated this literature and concluded that no recommendations could be made regarding the use of B6 and magnesium. In light of the weak methodology employed by the positive studies and the recent negative study, I cannot recommend B6 and magnesium megadoses on any basis other than as experimental treatment.

Gluten- and casein-free diets. Casein (found in dairy products) is said to form an endogenous opiate called casomorphine, whereas gluten (found in wheat, oats, barley, and rye) is said to break down to a peptide (gliadomorphine) that “acts” as an opiate.45 According to Garvey,45 these endogenous opiates are thought to find their way into the central nervous systems of vulnerable children, causing or contributing to autism. The rationale for their formation in autism is thought to be due to (1) insufficient enzyme activity in the gut, (2) an abnormally permeable gut, or (3) an abnormally permeable blood-brain barrier. In any case, this has caused some clinicians to try gluten- and/or casein-free diets in the hope that they can eliminate the “excess” opiate peptides and alleviate the symptoms of autism. One review of the literature was quite positive,46 but it was very uncritical of the methods used and failed to note the lack of control groups and any contribution of placebo, practice, or maturational effects on outcome. Millward et al.47 (Cochrane Database of Systematic Reviews) examined 29 studies assessing gluten- and casein-free diets for ASDs. Only 1 investigation met the reviewers’ criteria for a randomized clinical trial, this being a study of 20 children that found decreased autistic symptoms with diet but no effects on communication, cognition, or motor performance. The reviewers concluded that this is an important area of investigation and that large-scale, well-controlled studies are needed. At this stage, the gluten- and casein-free diets must be regarded as experimental.

Other unproven treatments. Other unproven treatments include dimethylglycine, essential fatty acid treatment, famotidine, vitamin A, and nonspecific chelation therapy.17 Other procedures that are not recommended include fMRI, allergy testing, hair analysis, chelation challenge testing, gut permeability studies, and stool analysis.9 Sensorimotor integration is a series of activities designed to improve vestibular, cerebellar, and other sensory function.22 Although it probably improves motor coordination (especially gross motor), there is no evidence of significant effect on core symptoms of autism.4,48 In the final analysis, the informed clinician’s instinct should be “Show me the data!” before resorting to such treatments. It is much easier
to generate would-be treatments than it is to test them in a programmatic manner.

CONCLUSION

To sum up, ASDs are enormously variable and present clinicians with many challenges. It is important to recognize this diversity, and it can be helpful to conceptualize clinical planning within a life-stage framework. It is also important to recognize that mental health professionals are likely to be one part of a complex treatment team; they may take a leadership role or may opt instead to collaborate with other members of the team. Regardless of the affiliations of team members, advocacy is likely to be an ongoing activity. One element of advocacy is advising parents and caregivers about the validity of the many treatments being proposed for helping patients with ASDs.

Few professionals are able to stay abreast of all legislative, educational, pharmacologic, health, and other developments that influence patients with ASDs. However, we are capable of knowing the resources in our own regions and the specialists (often including parents!) who may be in a position to help these families. When we encounter a barrier, we may need to stop and think seriously about who has the right resources to help a given family. Health professionals having possible solutions may be found in any combination of the following settings: (1) University Centers of Excellence in Developmental Disabilities, (2) most children’s hospitals, (3) mental retardation and developmental disabilities specialists, and (4) special state, county, and metropolitan information clearinghouses. By staying scientifically grounded, being open to constructive team input, and being mindful of the developmental stages patients must progress through, health professionals will be able to make many positive impacts in the lives of patients having ASDs.

Drug names: famotidine (Pepcid, Flucid, and others), secretin (Chirhostim and Secremax).

Disclosure of off-label usage: The author has determined that, to the best of his knowledge, famotidine, secretin, and dimethylglycine are not approved by the U.S. Food and Drug Administration for the treatment of autistic spectrum disorders.

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