Beyond the Roadblocks: Transitioning to Adulthood With Asperger’s Disorder

Diane H. Lawrence, Delores A. Alleckson, and Pamela Bjorklund

Growing up with Asperger’s disorder is complex and fraught with difficulty. Although the literature includes some research related to the transition of youth with Asperger’s disorder to school and employment, none pertains to the transition to adulthood and independent living. Although a marginal number of young adults with Asperger’s disorder eventually achieve independence, many of them continue to depend on families for supportive services. Currently, health care organizations and social services lack coherent, integrated systems to assist youth with Asperger’s disorder and their families with the out-of-home transition. To better facilitate the process, this article reviews the literature on Asperger’s disorder, leading to a comprehensive, evidence-based transition assessment guide framed by A. Maslow’s (1972) hierarchy of needs.

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PURPOSE

AUTISM SPECTRUM DISORDERS (ASDs) are neurodevelopmental disabilities resulting in a broad range of impairments in social relatedness, communication, and restricted patterns of interest. Neurological abnormalities in motor, sensory, and integrative functions can result in significant dysfunction (Tani, Newton, & Kaur, 2006). Impairments include difficulty in interpreting social cues and in relating to peers. Interactions are egocentric rather than reciprocal. Additional difficulties with executive function impair organizational capacity and contribute to the misinterpretation of social cues (Nordin & Gillberg, 1998).

The term autism spectrum disorder encompasses autistic disorder, Asperger’s disorder, and pervasive developmental disorder not otherwise specified (PDD-NOS; Towbin, Mauk, & Batshaw, 2002). Prevalence rates are estimated between 2.8 and 4.8 per thousand; however, the data may be imprecise due to small sample sizes and ongoing changes in the definition of ASD (Shtayermman, 2007). Growing up with an ASD is no small challenge. The transition to adult life is complex and fraught with difficulty.

Thus, this article provides an overview of the literature on ASD as it pertains to the transition of youth with Asperger’s disorder to adulthood. The review has led to the development of a comprehensive, evidence-based needs assessment process (Table 1; transition assessment guide) framed by Maslow’s (1972) hierarchy of needs (Figure 1).

BACKGROUND

In 1943, Leo Kanner first described autism in individuals who presented with neurodevelopmental disabilities and mental retardation (Klin & Volkmar, 2003). The following year, Hans Asperger, an Austrian pediatrician, described a similar condition, which he termed autistic psychopathy, in males who presented with similar symptoms but were higher functioning and not as withdrawn (Klin...
In 1981, Lorna Wing published cases like those described by Kanner of young females with mild mental retardation and early language delays, which she called Asperger's syndrome. Her labeling blurred the distinction between Kanner's description of autism and Asperger's identification of a related syndrome (Klin & Volkmar). Defined as Asperger's disorder in the Diagnostic and Statistical Manual, Fourth Edition, Text Revision, Asperger's syndrome is also used synonymously with high-functioning autism or PDD-NOS (Klin & Volkmar). The debate continues over the definitive differences between a diagnosis of Asperger's disorder and autism. Others question at what point a person with Asperger's disorder has a disability rather than an eccentric personality (Portway & Johnson, 2005).

For decades, ASDs have been recognized and treated as psychiatric disorders with characteristic symptoms including “deficits in the areas of social interaction and communication along with restrictive, stereotyped, and repetitive behaviors and interests” (Freitag, Kleser, Schneider, & von Gontard, 2007, p. 948). Perhaps because they are categorized as psychiatric disorders, the many physiological symptoms associated with ASDs are often overlooked or disregarded. Commonly overlooked symptoms include constipation, diarrhea, lethargy, night sweats, and inattention (Adams, 2007; Edelson, 2008). The error is compounded by the difficulty individuals with an ASD have in communicating their feelings and experiences. Because the diagnostic label does not speak to the individual’s unique strengths and weaknesses or to the wide range of possible prognoses, providers must individualize interventions to meet diverse, complex needs.

Although adolescence can be difficult for anyone, this developmental stage—characterized by rapid hormonal changes, a shift in reference group from parents to peers, and painful struggles to achieve individual and group identity—is especially challenging for those with Asperger’s disorder, who generally are unaware of their deficits and tend to experience their difficulties as external to themselves. These children often come to adolescence with a long history of social rejection. Their lack of peer relationships and characteristic history of school problems have led to a degree of demoralization and self-doubt not experienced by most of their age-mates. Because of the chronicity of the syndrome, those with Asperger’s disorder are well behind their peers in social and emotional development as defined by Erikson (1950). Lacking the resources to catch up, they are ill-prepared for the challenges of transitioning to adulthood. For parents worn thin over the years from daily struggles to meet their child’s multitudinous needs, the transition to adulthood with its associated tasks can seem overwhelming, complex, and beyond their effective management.

Although the literature on Asperger’s disorder includes some research related to the transition to school and employment, none pertains to the transition to independent living (Hurlbutt &

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### Table 1. Transition Assessment Guide

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<th>Physiological</th>
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<td>Can the youth consistently attend to instrumental ADLs?</td>
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<td>Can the youth shop for food? Plan a menu? Cook?</td>
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<td>Is the youth’s diet nutritionally sound?</td>
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<td>Can the youth follow a special diet, e.g., gluten- or casein-free?</td>
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<td>Can the youth follow a medication regimen?</td>
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<td>Can the youth refill medications? Self-administer them?</td>
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<td>Is the youth aware of and/or able to express health care needs to providers?</td>
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<td>What are the youth’s transportation needs? How can they be met?</td>
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<th>Safety/Security</th>
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<td>To what threats are the youth vulnerable? To what degree?</td>
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<td>How does the youth understand “staying safe”?</td>
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<td>Is the youth vulnerable to abusive relationships?</td>
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<td>Does the youth understand vulnerabilities related to internet use?</td>
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<td>Does the youth understand financial vulnerability?</td>
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<td>How to manage checkbooks/credit cards?</td>
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<td>What residential, vocational, or mental health services might the youth need?</td>
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<td>What are the youth’s sensory issues? What are the triggers?</td>
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<td>Does the youth require a guardian?</td>
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<th>Social (belonging)</th>
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<td>Does the youth have quality friendships?</td>
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<td>Does the youth stay emotionally safe in relationships? How?</td>
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<td>Does the youth have support of family?</td>
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<td>Does the youth have an intimate relationship?</td>
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<td>Where does the youth feel a sense of belonging? Can this be expanded?</td>
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<td>Does the youth experience depression or have other mental health needs?</td>
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<th>Ego (esteem)</th>
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<td>Where does the youth obtain recognition from others?</td>
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<td>What are the youth’s current sources of self-esteem?</td>
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<td>Does the youth obtain satisfaction from work/volunteering?</td>
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<td>In what areas does the youth excel? Can these be expanded?</td>
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<th>Self-actualization</th>
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<td>Does the youth have an identified creative outlet?</td>
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<td>Does the youth have a career goal?</td>
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<td>Does the youth have a vision for self-actualization? If so, how can it be supported?</td>
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Early childhood and school-age developmental issues in Asperger’s disorder have been well studied (Dymond, Gilson, & Myran, 2007; Klin & Volkmar, 2003; Williams White, Keonig, & Scahill, 2007); however, the literature minimally addresses the issues of adolescents and young adults. Sadly, this small body of literature points to dismal outcomes in the transition to independent living for young adults with Asperger’s disorder (Howlin, Goode, Hutton, & Rutter, 2004; Jennes-Coussens, Magill-Evans, & Koning, 2006; Nordin & Gillberg, 1998). Although a marginal number of these adults achieve independence, many of them continue to depend on families or supportive services (Howlin et al.; Jennes-Coussens et al.). Although an IQ of 70 was predictive of a successful transition in one study, other researchers found little difference in the outcomes of those with childhood IQs ranging from 70 to 100 (Barnhill, 2007; Howlin et al.).

Currently, health care organizations and social services lack coherent, integrated systems to assist youth with Asperger’s disorder and their families with the out-of-home transition. Typically, parents are sent from the physician’s office to the school system to social services and back to the health care system in a never-ending loop. When a youth with Asperger’s disorder leaves school, entitlement services are lost; the responsibility for coordination of services then falls to the parents, most of whom are ill-prepared to step in as case managers (Lounds, Mailick Seltzer, Greenberg, & Shattuck, 2007). Each system offers its best advice and assumes that parents can put it all together to develop an effective transition plan. Investigators have found that information about specialized services is difficult for parents to obtain and collaboration among health professionals and schools is limited; professionals do not always communicate effectively or consider parents’ concerns (Barnhill, 2007).

Because of the uniqueness and diversity of symptom presentations and prognoses in Asperger’s disorder, parents generally have the expertise to most accurately assess their child’s unique strengths, deficits, and needs. However, they cannot facilitate an effective transition without coordinated, interdisciplinary support. The symptoms of Asperger’s disorder are especially apparent during the stressful transition process (Jennes-Coussens et al., 2006). With new stressors and little information to effect a successful transition—and with awareness of the likelihood of their soon-to-be adult child’s continued dependence—parents might well feel like Alice in Wonderland, desperately trying to quickly find the key to open the door to transition services matched to their adolescent’s unique needs. Nurses caring for families with youth who have Asperger’s disorder need to understand the
challenges these families face in planning for a successful transition to adulthood, which depends first and foremost on the careful, systematic assessment of the youth’s comprehensive needs.

**PARENTAL CONCERNS**

The first step in the assessment process is to review the individual’s and parents’ goals and knowledge of deficits and needs. Although discrepant goals between parents and emancipating offspring are typical, the discrepancy can be more intense in Asperger’s families for several reasons. First, the individual with Asperger’s disorder may not be completely aware of his or her deficits. Parents, on the other hand, are very aware of them. Protectiveness is a common theme among parents who are profoundly aware of their child’s vulnerabilities, whereas professionals frequently discount parents’ concerns and label them overly protective (Portway & Johnson, 2005). Second, graduation and transition to adulthood frequently trigger feelings of grief in parents of children with disabilities. As they observe their child’s peers graduate and move on to college, parents once again experience the poignant loss associated with recognition of “what should have been” compared to “what really is” (Schreier & Droes, 2006). Third, although it is critically important, parents do not necessarily agree on their child’s level of disability, in which case triangulation among family members can preclude a successful transition. Complete assessment of both the individual’s abilities and parents’ concerns is vital to the success of the transition.

**PHYSIOLOGICAL NEEDS**

Often overlooked, the physiological concerns and physical welfare of individuals with Asperger’s disorder are critically important. Basic considerations include the ability to maintain bodily integrity with healthy diets, exercise programs, and routine activities of daily living (ADLs) and to secure transportation, independent or supportive housing, and community integration.

**Diet and Exercise**

Every child with an ASD has some combination of clinical and laboratory abnormalities (Kidd, 2007). These include (a) congenital inborn errors of metabolism; (b) biochemical peculiarities that result in multiple nutritional deficits; (c) neurotransmitter imbalances that result in abnormal processing of expressive information; (d) gastrointestinal abnormalities that lead to maldigestion, malabsorption, chronic diarrhea, constipation, and abdominal discomfort; (e) impaired liver detoxification; and (f) immune system abnormalities (Kidd). Some practitioners familiar with autism agree that modifying the diet should be a priority (Jepson, 2007). “Many parents report that when they closely regulate their child’s diet, they have observed improvement in overall functioning, and when dietary restraints are relaxed, the child often worsens” (Kidd, p. 474). Some investigators suggest that there is an adverse brain effect associated with dietary casein and gluten, most likely due to opioid-acting peptides metabolically generated from these proteins: “Gluten and casein peptides can attach to the opiate receptors in the brain and in the body. Opiates act as both neurotransmitters and immunodulators and can interfere with our natural endogenous opiate function, changing the balance of the neurotransmitters” (Jepson, p. 247).

Although food-derived opiates are not as powerful as drugs, the biochemical effects are comparable. Abrupt discontinuation of casein and gluten from the diet can cause withdrawal symptoms including behavioral agitation, aggression and self-abuse, anxiety, lethargy, diarrhea, constipation, and inattention (Adams, 2007; Edelson, 2008). Full clearance of dietary casein–gluten is a long process, and withdrawal symptoms may be evident for 3 months or longer (Lucarelli et al., 1995). Gluten exclusion requires the removal of wheat, barley, rye, and oats from the diet. The elimination process takes approximately 3 to 4 weeks, and a trial of 3 months is usually adequate to assess benefits (Lucarelli et al.). A two-step, phased withdrawal is recommended. The first phase removes casein by eliminating milk and other dairy products from the diet. The second phase eliminates gluten from the diet. Sixty-six percent of subjects showed benefits within the first 2 weeks of the elimination process, including improvements in social isolation, eye contact, mutism, learning skills, hyperactivity, stereotypic activity, and panic attacks (Lucarelli et al.). Those who have benefited from a gluten–casein-free diet must determine whether they can maintain the regimen independently or will require group home structure and supervision. Unfortunately, the sensory hypersensitivity and clumsiness characteristic of Asperger’s disorder make exercise less enjoyable, which can diminish motivation to...
participate in physical activities and affect sleep and overall health (Jennes-Coussens et al., 2006).

ADLs and Transportation

The person with Asperger’s disorder typically acquires ADLs under the guidance of parents, who offer a 24-hour commitment to help structure care of the body with daily routines (Portway & Johnson, 2005). Sensory (over)stimulation, environmental demands, and executive dysfunction combine to limit independent, timely, and consistent attention to ADLs. Physical health problems, discomfort and pain, medication effects, sleep disturbances, and fatigue, all of which are common in Asperger’s disorder, also disrupt consistent attention to ADLs (Barnhill, 2007). The degree of regularity with which the person attends to his or her needs without prompting from parents has implications for independent living. Key to success posttransition is the identification of interventions that have worked in the home and replication of those adaptations in the new environment. Examples of daily living skills include (a) grooming and hygiene; (b) appropriate choices of nutrition; (c) appropriate care of clothing; (d) responsibility for personal belongings; (e) knowing how to respond to symptoms of illness, accidents, or emergencies; and (f) appropriate use of leisure time. Independent living skills also include money management, housekeeping, consumer skills, and use of public transportation. A component of independence relies on the ability to travel to appointments, school, jobs, and shopping centers. Whether the individual possesses the aptitude to drive independently or uses public transportation, he or she must have mastered basic directional skills, which can be compromised by executive dysfunction. Available through occupational therapy, a functional assessment to determine the interests, needs, preferences, and abilities of an individual in terms of both daily living and occupational skills can identify strengths and deficits and provide a basis for more effective transition planning (Clark, 2007).

Housing

The transition from the family home to a group home, semi-, or independent living environment can be difficult for young adults with Asperger’s disorder. Their distractibility and organizational and sequencing difficulties interfere with their ability to function independently in the community, where they continue to demonstrate the same difficulties in understanding the world and others’ expectations as they did as children (Van Bourgon-dien & Woods, 1992). Ideally, the diagnosis, strengths, and needs of the individual determine the optimal living environment. However, placement often depends on where there is an opening and on funding sources, for example, Mental Retardation/Related Condition waiver (MR/RC), Community Alternatives for Disabled Individual, or Group Residential Housing (Consumer Directed Supports, 2009). Living choices can be limited by the individual’s deficits.

In the state of Minnesota, individuals with Asperger’s disorder may have a county case manager who is mandated to help the family select the optimal living environment and secure funding for it. If the individual does not qualify for case management services, Consumer Directed Community Supports (CDCS) might assist. CDCS was first approved by the federal government as a service of the MR/RC in December of 1997 (Consumer Directed Supports, 2009). As part of a coordinated department of human services system of supports to enable people with disabilities to live where and with whom they choose in the community, the program allows consumers to direct the delivery of services and supports, including deciding when services and supports are needed, choosing or designing the services and supports that fit the individual’s needs, and hiring the people the family wants to deliver those services and supports (Consumer Directed Supports).

Group homes, licensed by the state department of human services under Adult Foster Care, are another resource. In the state of Minnesota, an adult foster care home is one that provides sleeping accommodations and services for one to five adults with private or shared rooms and dining areas, bathrooms, and other spaces that are shared family style. Adult foster care homes can offer a wide range of services, and the consumer must clarify service offerings and expectations. Before selecting the site, the individual and family should ask specific questions about such things as staffing patterns, training specific to Asperger’s disorder, management of behavioral issues, ability to facilitate sensory and community integration, and dietary considerations.

Community integration

Since 1972, the state of North Carolina has demonstrated great success in community
integration with the statewide program called Treatment and Education of Autistic and Related Communications Handicapped Children (TEACCH), which became a permanent state agency mandated to serve children with autism and their families. With outcome data from this early experience, the program learned that most children improved when parents and professionals worked collaboratively to implement interventions. In 1979, TEACCH’s mandate was expanded to serve adolescents, adults, and their families. Over the years, its successful work with children was adapted and applied to adolescents and adults. The program’s earliest emphasis was placed on parent/professional collaboration to optimize the best possible outcomes for individuals with autism. Thus, as an individual with autism transitioned to vocational, residential, or other community settings, their families continued to play a crucial role. Parents remained the “experts” with valuable information about their grown children to share with future job coaches, caregivers, residential staff, and other treatment providers. The TEACCH philosophy emphasizes a positive, proactive approach to helping an individual learn new skills. It also emphasizes environmental adaptation to autism-related deficits (Schopler, 1994). This two-pronged approach involves the structured teaching of the functional skills the individual shows readiness to learn while at the same time adapting the environment in ways that allow the individual to utilize available strengths to compensate for areas of deficit.

Adults with autism have significantly more problems with ritualistic behaviors and coping with change than those without autism (Van Bourgondien & Woods, 1992). They have a tendency to easily get upset and agitated, which significantly impedes adaptation especially to settings that lack supportive structures. However, minimizing change is not necessarily helpful. “Individuals with autism need predictability in their environment and not necessarily repetition. For some individuals with autism, engaging in the exact same routine on the job every day appears to have a negative effect on their motivation and work performance” (Van Bourgondien & Woods, p. 232).

Concrete daily schedules can help the individual comprehend the day’s sequence and predict what will happen next. Visual schedules allow workers with Asperger’s disorder to anticipate what work they will be doing without having the monotony of doing the same thing every day. In residential life, routines supported by visual schedules help clients with Asperger’s disorder organize and adhere to ADLs, such as showering or brushing teeth. Frequently checking one’s daily schedule and following directions from work lists are two routines that improve functioning in community settings (Mesibov, Schopler, & Hearsey, 1994).

SAFETY AND SECURITY

Vulnerability

Their naivete and difficulty interpreting social cues leave youth with Asperger’s disorder vulnerable to many forms of exploitation, for example, in finances, friendships, or sexual encounters. Depending on the individual’s level of functioning and vulnerability, parents may want to explore the need for guardianship as an element of transition planning.

Sensory Overload

Sensory overload, most likely caused by deficits in sensory integration, may be the primary challenge encountered by adults with Asperger’s disorder. It presents a huge obstacle to effectively organize and manage a safe, secure daily structure. For example, noise sensitivity and oversensitivity to touch can induce pain and discomfort, precipitate behavioral problems, and affect energy level, sleep, and ability to work (Jennes-Coussens et al., 2006). Typically, the brain’s sensory systems work in an integrated way to help one make sense of the world in order to act effectively on and within it (Myles, Dunn, & Orr, 2002).Likening the body to a computer, the central nervous system (CNS) or brain is the central processing unit that receives, interprets, organizes, and transmits messages to the rest of the body. It helps the individual to regard, disregard, seek out, or avoid sensation to maintain or increase comfort, excitement, rest, and positive interactions with objects and people. It also influences how the individual attempts to avoid anything that is painful, uncomfortable, or stressful.

Sensory integration is defined as “the organization of sensation for use” (Ayers, 1979, p. 5). The capacity for sensory integration means the CNS can operate in an ongoing, dynamic, coordinated way to process and integrate information from multiple sensory systems. The outcomes of this process can
be seen in the individual’s organized reactions and responses to situations that involve multiple sensory inputs, for example, bright lights, crowds, loud noises, and odors. Thus, sensory integration is a never-ending process of coordinating sensory inputs and mediating the connections between sensory inputs and resultant behaviors (Ayers). To the degree the brain’s capacity for sensory integration is impaired, one cannot respond with adaptive behavior to sensory stimuli experienced as uncomfortable, intense, painful, or stressful. In short, chaotic inputs (disintegrated sensory stimuli) lead to chaotic outputs (disorganized behavior).

Sensory input can have both a facilitating and inhibiting effect on the overall nervous system (Heller, 2002). Some inputs result in a state of alertness and readiness to respond. Other inputs may be disregarded or inhibited, altering possibilities for behavioral response. Modulation of sensory input balances and regulates facilitative and inhibitory effects. When modulating processes are intact, the nervous system can respond to some sensory inputs while disregarding others. Thus, an individual can recognize and respond to familiar inputs without attending to them in ways that would distract from the intended focus. Poorly modulated sensory input may result in CNS over- or underreactivity along with behavioral responses not appropriate to meet the demands of the situation (Ayers, 1979). Neuroscientists have begun to locate evidence that sensory input evokes numerous physiological changes in the body (Santangelo & Tsatsanis, 2005). With input as subtle as a smell or a sound, individuals with Asperger's disorder often react strongly and sometimes disruptively to commonplace, seemingly innocuous sensory stimuli.

Myles, Dunn, and Orr (2002), for example, studied 42 children and adolescents with Asperger's disorder and found that sensory processing was clearly problematic. Approximately two thirds of the participants exhibited emotional and social difficulties related to sensory processing. Seventy percent of those participants experienced problems in modulation as it related to movement affecting activity level, sensory input affecting emotional responses, and visual input affecting emotional responses and activity level. According to Dunn (1999), more than 50% of children and adolescents with Asperger’s disorder have difficulties in auditory, vestibular, touch, oral, and multisensory areas as measured by the Sensory Profile, which is a 125-item, norm-referenced questionnaire that describes behavioral responses to various sensory experiences, including reactions to specific sensory stimuli and ability to modulate reactions efficiently.

Clearly, deficits in sensory processing and integration have an enormous and often destructive impact on children and adolescents with Asperger’s disorder, interfering with their ability to tolerate stress, adapt to change, make and keep friends, or meet the challenges of full participation in the larger society. Even slight changes in daily structure can result in sensory overload, increased anxiety, disruptive behavior, and explosive incidents (Barnhill, 2007). To obviate unnecessary medication and facilitate long-term adaptation, an occupational therapy assessment should be obtained. It can provide valuable information for the selection and use of individualized sensory integration strategies. An understanding of the underlying deficits in sensory integration can facilitate planning for supportive interventions across academic, vocational, clinical, or residential venues. Of course, children and adolescents with Asperger’s disorder also may engage in behaviors that are not sensory based, and these may be best addressed with an appropriate behavior management plan. Nevertheless, an occupational therapy assessment should be part of any Asperger’s transition plan.

Pharmacotherapy

Pharmacotherapy can mitigate some safety concerns with respect to clients with Asperger’s disorder, and pharmacologic research certainly has the potential to lead to improved treatments and a better quality of life for the person with Asperger’s disorder. However, this population is extremely difficult to study in a controlled fashion due to extreme symptom heterogeneity, the need for long-term monitoring, and the cardinal features of the disorder, for example, impairments in social connection and communication (Santangelo & Tsatsanis, 2005). Most pharmacological interventions have been geared to managing symptoms of aggression, self-injury, inattention, and stereotyped movement (Santangelo & Tsatsanis). To date, no single medication or type of medication has been proven useful in treating the core social or pragmatic language deficits of autism (Towbin et al., 2002). Most clinicians believe environmental and educational interventions are necessary and beneficial. Yet, they most often rely solely on
medication, sometimes at the request of the patient or family, and it may not serve the patient well in all circumstances.

Anyone who takes responsibility for the pharmacologic treatment must understand the phenomenology and course of Asperger’s disorder. The specific constellation of symptoms exhibited by an individual determines the chosen treatment. The range and heterogeneity of symptoms and possible prognoses introduce sizeable challenges with respect to choosing appropriate treatments. Symptoms common to Asperger’s disorder can mimic other psychiatric disorders, and diagnostic confusion can lead to inappropriate, unhelpful, even detrimental treatment plans. Both the person with Asperger’s and his or her caregivers must share some understanding of target symptoms, triggers, warning signs, and intended medication effects. Group home personnel who administer medications must also understand the medication’s purpose and intended effects. Families, residents, and residential staff sometimes expect that response to pharmacologic treatment will be rapid and complete with no need for behavioral psychotherapies. However, all must understand that there are no “magic bullets” when it comes to treating Asperger’s disorder.

Conventional antipsychotics are often the pharmacologic treatment of choice, and haloperidol has been studied the most (Buitelaar & Willemsen-Swinkels, 2000). Short-term haloperidol was consistently superior to placebo in decreasing motor stereotypy, hyperactivity, withdrawal, and negativism in Asperger’s subjects. Side effects included dystonic reactions, acute dyskinesia, parkinsonism, akathisia, and autonomic and cardiovascular symptoms. The atypical antipsychotic risperidone has also shown efficacy in reducing irritability, aggression, repetitive behaviors, and other affective symptoms with mild sedation the most prominent side effect (McCraen, McGough, & Shah, 2002). Adverse effects included increased appetite and weight gain, fatigue, and drowsiness. In 2006, risperidone was approved by the Food and Drug Administration for the symptomatic treatment of irritability in autistic children and adolescents (2002; FDA, 2006).

The ability to self-manage a medication regimen varies widely among persons with Asperger’s disorder and requires careful assessment. They can be more or less knowledgeable about medication indications, dosing schedules, side effects, how to fill or reorder prescriptions, or when and how to seek health care. When anxious or overloaded by sensory stimuli, they may not be able to express their needs in socially appropriate ways and can alienate or frighten others. Caregivers are more helpful to the degree they understand the person’s triggers and specific sensory modulation regimen. Protocols written by parents, carried by clients, and easily accessed by care providers can be enormously helpful under conditions of sensory overload.

**Psychotherapy**

Although older children and adolescents most often are offered a combination of cognitive and behavioral therapies (CBT), there is no established evidence base for the psychotherapeutic treatment of Asperger’s disorder (Roth & Fonagy, 2005). CBT is a brief, structured form of psychotherapy originally developed for the treatment of depression. It is problem oriented and focused on effective coping skills for the psychological and situational problems that contribute to the client’s distress (Beck, Rush, Shaw, & Emery, 1979). Most psychotherapy is predicated on the ability of a client to form a therapeutic alliance and to share thoughts and feelings.

However, the serious difficulties clients with Asperger’s disorder have with reciprocal social interaction, evident in both verbal and nonverbal communication, make it difficult to form and maintain one-to-one therapeutic relationships. Hare and Flood (2000) suggest that “[i]t may be more useful not to make an empathetic therapeutic relationship the basis of clinical work with a person with a diagnosis of [Asperger’s disorder]. Instead, explicit agreements on the joint purpose of the sessions may be more appropriate, given that the problems in empathic subjectivity may be central to the person’s social difficulties” (p. 12). In other words, the therapeutic contract is organized around a directed, structured approach to achieve targeted behavioral goals and not necessarily around a “relationship.”

The person with Asperger’s disorder may have unusual ways of expressing thoughts and emotions, including specific names for symptoms and experiences; the therapist should discover and use these specific terms (Gaus, 2007). Renaming symptoms in the patient’s own words is a common technique in CBT for children and adolescents, but it may be
equally important in working with adults with Asperger’s disorder who also interpret language in idiosyncratic and literal ways (Anderson & Morris, 2006). During sessions, therapists can also helpfully use multiple sensory modalities to obtain and utilize information about thoughts and feelings while affording their clients with Asperger’s disorder some distance from uncomfortable interpersonal interaction—for example, by using visual materials like diaries and diagrams, communicating in writing as well as verbally, listening to tape recordings, or working together on a computer to meet therapeutic goals. Involving family members or staff from the client’s home or school can facilitate the generalization of new skills to other functional areas (Anderson & Morris). Whether behavioral or pharmacological, treatment interventions should target specific identified symptoms or behaviors to assist the clinician in monitoring the course of treatment. Integrated behavioral and pharmacological care must establish realistic expectations; optimize the home, school, and/or work environment; implement strong parental collaboration; and focus on target symptoms and behaviors (Towbin et al., 2002).

Comorbid Illness

The possibility of a comorbid mental health condition constitutes another threat to the safety and security of persons with Asperger’s disorder. Common comorbid conditions include depression, anxiety, obsessive–compulsive disorder, Tourette’s syndrome, and learning disabilities (Higgins, Koch, Boughfman, & Vierstra, 2008). Studies show that depression is the most common comorbid psychiatric diagnosis in Asperger’s disorder, which is complicated by the fact that these individuals have difficulty understanding and expressing emotions. Repeated social failures, self-doubt, low self-esteem, and the losses inherent in transitioning to adulthood may contribute to depressive symptoms in youth with Asperger’s disorder, which can range from an increase in oppositional or aggressive behaviors and outbursts to increases in self-isolation, irritability, and sadness (Bauminger, Shulman, & Agam, 2003). Catatonia also has been documented along with psychomotor retardation and diminished self-care. A family history of depression in a first-degree relative can be a significant diagnostic indicator (Higgins et al.).

Parents, caregivers, and role models need education to identify warning signs and possible symptoms of depression. Changes in behavior are not always part of the Asperger’s syndrome; rather, they may indicate an underlying mood disorder (Bauminger et al.).

LOVE AND BELONGING

Friendships

Social impairments in Asperger’s disorder make it difficult for those affected to comprehend social rules or function within expected social norms, which often leads to interpersonal rejection, exclusion from social groups, and other forms of social failure. The impairments are as diverse as the exhibited symptoms. Common impairments in social pragmatics include a lack of reciprocity in social exchange, for example, the inability to understand another’s point of view or take turns in conversation; poor speech prosody, that is, improper tonal inflections or the propensity to perseverate on a narrow range of topics; and difficulty comprehending and expressing emotions or other abstractions like metaphorical or colloquial speech (Williams White et al., 2007). Impairment in executive function contributes to behavioral rigidity, especially in social interactions (Kidd, 2007).

Because they frequently report a desire for social relationships, researchers question whether individuals with Asperger’s disorder prefer not to socialize with peers or whether their social deficits prevent them from social interaction (Higgins et al., 2008; Roth & Fonagy, 2005). Their interpretation of what constitutes socialization or a friendship may differ from those not diagnosed with Asperger’s disorder. For example, Bauminger and Kasari (2000) found that participants with Asperger’s disorder were able to identify a close friend; however, their mothers reported that they frequently ignored their identified “friends.” The mothers described socialization that focused on activities like video games that allowed very little social interaction. Although youth with Asperger’s disorder perceived themselves as having friends, they were unable to grasp all the elements of a reciprocal friendship (Bauminger & Kasari).

Typically, individuals with Asperger’s disorder are perceived as odd or peculiar because of their limited interests and their rigid, restricted, repetitive, or otherwise unusual behavior.
peculiarities can set them up for bullying by peers or other forms of victimization (Shtayermman, 2007). Social failure of this sort can lead to feelings of loneliness; however, youth with Asperger’s disorder have difficulty feeling or recognizing emotions. They do not understand loneliness in typical terms, that is, as an emotional experience that depends on affective bonding with another person. Although they may perceive themselves as having friends, these “friendships” do not necessarily entail physical or emotional proximity (Bauminger & Kasari, 2000). Rather, youth with Asperger’s disorder may gravitate to the Internet where they can have friends yet never have physical contact with them. Unsurprisingly, because of their naivete, their difficulty interpreting social nuances and cues, and the ongoing potential for peer victimization on- and off-line, youth with Asperger’s disorder can become increasingly isolative (and isolated) during adolescence. A peer mentor can be an invaluable resource, serving as a role model, confidant, and source of social skills information and feedback. Locating a peer mentor can help insure a successful transition plan.

**Romantic Interests**

Lack of social competence poses a serious threat to love and a sense of belonging. Like most other human beings, people with Asperger’s disorder desire romantic relationships and intimacy; lack of social competence is cited most often for lack of success in this area (Barnhill, 2007; Jennes-Coussens et al., 2006; Stokes, Newton, & Kaur, 2007). Common difficulties include misinterpretation of social cues and body language and inappropriate verbal or physical mannerisms. Stokes et al. found that individuals with Asperger’s disorder were often perceived as stalking the objects of their romantic interest due to socially unacceptable behaviors that included obsessional interest, aggressive pursuit, inappropriate touch, threats to the individual, and threats of self-harm.

**SELF-ESTEEM**

Social rejection and repeated social failure are inimical to the development of healthy self-esteem. For persons with Asperger’s disorder, “there may be constant pressure to fit in with the demands of a society that fails to understand their needs or difficulties” (Howlin, 2000, p. 64). Inability to interpret the rules of society or meet the expectations of one’s culture is demoralizing beyond measure. In the face of constant rejection, some young adults with Asperger’s disorder further retreat from the world—to the security of their own rooms or apartments and to the safety of restricted interests. The pain of aloneness is preferable to the pain of rejection; and the tasks of young adulthood, focused on incipient relationships and careers, go unmet (Erikson, 1950). To the degree needs are met successfully at lower levels of Maslow’s hierarchy, targeted interventions to build self-esteem might also succeed. Clearly, opportunities for success must be maximized. Strengths must be identified, and opportunities to regularly exercise them must be structured into the daily routine.

**SELF-ACTUALIZATION**

Self-actualization entails the full development of one’s abilities and ambitions. Although gainful employment does not insure it, satisfying work presents an opportunity for self-actualization. Employment in Asperger’s disorder has not been well studied (Hurlbutt & Chalmers, 2004). Portway and Johnson (2005) found that only 7 of 25 participants in their study were employed, 3 were in supported employment, and the remaining 14 were unemployed. The job interview is itself a barrier to employment (McCraken et al., 2002). Although people with Asperger’s disorder may possess job skills, their relative lack of social skills is readily apparent on interview (McCraken et al.). Studies of supportive employment under the direction of a mentor or job coach indicate that flexible schedules, job sharing, and active support during the first few weeks of employment are helpful (Hurlbutt & Chalmers; Nesbitt, 2000; Portway & Johnson). Support at the work site and flexible schedules may be the key to career attainment for at least some people with Asperger’s disorder.

**CONCLUSION**

Transition to adulthood presents a unique set of challenges for youth with Asperger’s disorder. To facilitate a successful transition, comprehensive needs must be identified and addressed before the individual leaves home. Because individuals with Asperger’s disorder adapt slowly to change, the idea of a transition should be introduced slowly and early with sufficient opportunities to practice, for example, at weekend or summer camps. Parents’ concerns about the safety of their child must also be
identified and addressed; they will require support for their own emotional needs. Indeed, it takes time for all family members to adapt to a changing family structure with all its attendant emotions. Advanced practice nurses who work with youth with Asperger’s disorder and their families can collaborate with them to create an individualized transition plan that identifies needs, concerns, and goals and plan ahead to meet them. Organized around Maslow’s hierarchy of needs (Figure 1), a transition assessment guide (Table 1) lists some of the important questions to ask in preparing an individualized transition plan.

REFERENCES


