

## Care of Patients With Autism Spectrum Disorder Undergoing Surgery for Cancer

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M.J., a 28-year-old nonverbal autistic male, was referred to a comprehensive cancer center for a second opinion regarding recurrent metastatic mixed nonseminomatous germ cell testicular cancer in the left testis. M.J.'s medical history included an untreated cryptorchidism (an undescended right testicle) but his left testicle was normal. M.J. was diagnosed with autism at age 2 and lives at home with his mother and father. He had been attending a day program prior to diagnosis and treatment of testicular cancer. His younger sister is a special education teacher and is very involved in his care.

M.J. was diagnosed with cancer 18 months prior to his visit to the cancer center when his mother discovered a lump in his left testicle while bathing him. He underwent an inguinal orchiectomy at a local hospital. Pathology revealed an 80% bridge cell and 20% immature teratoma. No complications from the surgery were reported; however, a computed tomography scan after surgery revealed metastatic disease in his lungs and retroperitoneal areas. He was treated with four cycles of cisplatin and etoposide. M.J. was intubated and sedated during the first two cycles of chemotherapy because of behavior issues. Aspiration pneumonia resulted from being ventilated and complicated his recovery. M.J.'s mother stayed with him in the hospital for the last two cycles and reported that they walked almost continuously for the duration of each hospital stay. A computed tomography scan done at the completion of

chemotherapy revealed a residual 8 cm cystic retroperitoneal mass consistent with nodal metastasis. The left kidney was displaced by the retroperitoneal tumor. The lung metastases had resolved.

The urologic surgeon at the comprehensive cancer center believed that M.J. was a candidate for a retroperitoneal lymph node dissection despite an increased risk of complications after surgery from M.J.'s autism. M.J.'s behavior in the outpatient clinic had been difficult. He was unable to sit still for a physical examination and spent most of the visit running up and down the halls. Realizing that certain arrangements would be needed during M.J.'s hospital stay, the surgeon notified the intensive care unit's clinical manager. The clinical manager and the clinical nurse specialist coordinated a literature search on autism and general needs of patients with autism. The clinical manager also visited M.J.'s home to meet him and his family and identify his needs prior to admission.

The retroperitoneal bilateral lymph node dissection was completed but was complicated by a right renal artery injury that was repaired by vascular surgery. Bilateral ureteral stents were put in place. M.J. remained ventilated and sedated in the intensive care unit so he would not injure himself or dislodge any tubes. He was extubated the day after the surgery, but progressive dyspnea with desaturation required reintubation the following day. M.J.'s chest x-ray also showed evidence of bilateral aspiration pneumonia. He was

extubated 12 days after surgery; however, he had developed bilateral pleural effusions that were drained and a right pigtail catheter was placed. M.J. was breathing normally when he was discharged. M.J.'s creatinine also was elevated after surgery. A renal vascular ultrasound revealed that no blood was flowing to the right kidney. The right stent was left in place until six days after surgery, and his creatinine level slowly returned to normal. The urinary catheter was removed 18 days after surgery.

M.J. was NPO for the first two weeks following surgery. He had minimal oral intake after extubation. An abdominal computed tomography scan revealed a large amount of ascites. A pigtail catheter was placed after several abdominal paracenteses because a chylous leak was the suspected cause of the ascites. Liver function tests and amylase and lipase levels also revealed pancreatitis. A peripherally inserted central catheter line was placed so total parenteral nutrition could be started. M.J. was NPO again.

M.J. experienced numerous complications from the surgery and his emotional and cognitive impairments, but he finally was discharged—on total parenteral nutrition and with an abdominal pigtail catheter in place—37 days after his surgery.

### What is autism and how does it affect cognitive and emotional functioning?

Autism spectrum disorders (ASDs) or pervasive developmental disorders (PDDs) are

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terms for a continuum of neurodevelopmental disorders, all of which are characterized by social (thinking, feeling, and relating to others), communication (verbal and nonverbal), and behavior (rigid, repetitive, and stereotyped) impairments. The disorders usually are diagnosed in early childhood. Autistic disorder (classic autism, early infantile autism, or Kanner disorder) is the most severe form, followed by PDD, not otherwise specified PDD, and Asperger syndrome, a form of high-functioning autism. Rett syndrome and childhood disintegrative disorder are rare but severe disorders also classified as PDDs (Augustyn, 2007; Strock, 2004).

Autism occurs before age three (American Psychiatric Association [APA], 2000). Delayed development or abnormal functioning will fall into at least one of three categories. Social interaction impairment may be manifested by an inability to use nonverbal communication or the lack of peer relationships. Communication impairments may be manifested by delayed or lack of speech development or, if the person can speak, an inability to have a conversation. Restricted or stereotyped patterns of behavior or interests may be manifested by persistent fixation with objects or interests, inflexible adherence to nonfunctional routines, or repetitive motor mannerisms.

### **What ethical issues arise when a patient with autism is considered for surgery?**

The incidence of autism is on the rise, although reasons are unclear (Dorman, 2005). Advances in surgical techniques and in the treatment of autistic children will increase the number undergoing major surgery. Ethical principles, including those of autonomy, beneficence, and nonmaleficence, should be considered before surgery. Autonomy implies that the patient understands the consequences of his or her decisions. Beneficence involves making decisions that are best for the patient. Nonmaleficence means that no harm is done to the patient, either through acts of commission or omission. The right to informed consent still applies, even if a person is incapacitated (autonomy) or lacks physical or mental abilities resulting in an inability to manage personal care, property, or finances (Nolo, 2007a). Incompetence is the inability, as determined by a court, to handle personal or financial affairs (Nolo, 2007b). Being incompetent or incapacitated is the basis for transferring a patient's right to informed consent to a legally authorized decision maker (Bernat, 2004). Bernat stated that when a patient is incompetent, family can be an informal surrogate when the following criteria are established.

- Family members agree on the desired course of action.
- Family members are trying to make the decision that the patient would make or act in the patient's best interest.
- Decisions are consistent with good medical practice.

Some individuals with autism who have normal intelligence (Volmar, Klin, & Schultz, 2005), as well as those with Asperger syndrome, may be able to give informed consent for their medical management. That was not the case with M.J.

M.J. was incapacitated because of his cognitive impairment but had not been declared incompetent by a court. Therefore, consent was obtained from his parents, his legal guardians, even though they did not have a legal durable medical power of attorney because all three of Bernat's (2004) criteria had been met. M.J.'s parents had always made his medical decisions and believed that they were acting in his best interest (beneficence). M.J.'s parents were in agreement and the decisions were consistent with good medical practice. Because M.J. had no durable power of attorney and no written advance directive, his parents verbally indicated that everything should be done to save him. The hospital's social work department helped the family create a legal durable medical power of attorney and written advance directive.

### **What strategies can be used to communicate with a nonverbal patient with autism?**

Verbal and nonverbal communication impairments are criteria inherent to an autism diagnosis. Common examples include little or no use of nonverbal behaviors (e.g., eye-to-eye gaze, facial expressions, body postures, gestures); failure to develop peer relationships at an appropriate developmental level; a lack of desire to share enjoyment, interests, or achievements with others; and lack of social or emotional reciprocity. Communication issues may include delayed or total lack of speech, inability to initiate or sustain a conversation, use of repeated words, and excess make-believe play. Possible repetitive and stereotyped patterns of behavior include inflexibility with rituals or routines, repetitive motor mannerisms, and preoccupation with parts of objects (APA, 2000; Kutscher, 2006). Nonverbal individuals with ASD can exhibit intentional, gestural, and vocalized communication (Stokes, 2007).

The visit to M.J.'s home prior to his hospitalization was helpful in establishing communication techniques by observing M.J. interacting with family and strangers in a comfortable, safe environment. M.J. had marked speech impairment and made limited gestures to indicate what he wanted, but he could make grunting sounds and shake his head positively or negatively when asked simple questions (gestural communication). He also was able to follow some simple instructions. M.J. was observed to purposefully answer a question the opposite way of what would be expected to tease his mother. He would repeat this several times before answering correctly, which elicited a hug from his mother. The intentional communication and positive reaction to touch are unusual traits for a person with ASD.

Stokes (2007) suggested that when a person can anticipate an outcome from his or her communication, regardless of the form, intent is demonstrated. This learned behavior was used during M.J.'s hospital stay as a means of positive reinforcement.

M.J. increased the tone of his grunts if he became impatient or did not get what he wanted—a type of communication called vocalization (Stokes, 2007). M.J. sat with his mother while she talked to healthcare providers (positive social reciprocity), although he constantly flicked a light switch on and off (repetitive motor mannerism). His mother said this meant he was nervous, probably because the healthcare team was unfamiliar to him. Understanding M.J.'s rituals and communication strategies helped the team adapt behavior and strategies to directly communicate with M.J.

### **What is the optimal care environment for patients with autism?**

Patients with autism are difficult to manage in a hospital setting because they can become anxious and agitated by changes in routine or environment. Waking in a strange place and increased sensory input, particularly in unfamiliar surroundings, can be alarming. Reducing noise, movement, and light can have a calming effect (Van der Walt & Moran, 2001). Patients with autism have difficulty adjusting to unfamiliar environments and caregivers, an issue that is accentuated by a hospital stay (Bachenberg, 1998). Allison and Smith (1998) suggested that a daily schedule and objects from home help decrease anxiety and agitation. Identifying a patient's specific likes and dislikes enables the healthcare team to avoid activities and situations that cause distress (Van der Walt & Moran). Staff consistency should be a priority (Gabriel & Gluck, 1973). Patients with ASD rely on caregivers to interpret their needs to staff, particularly if they use alternative forms of communication, such as sounds or facial expressions, so a caregiver must be present at all times.

For M.J., a nursing goal was to provide a predictable, consistent, familiar, low-stimulus environment, including caring for him in one place during his entire hospital stay, in a quiet, secluded room just outside of the intensive care unit where a family member could stay with him at all times. His favorite videos, pictures, and stuffed animals were brought from home. Volunteer caregivers were limited. M.J. was given time to wake in the morning and see his mother before nursing care began. A routine was established and adhered to as much as possible. M.J. seemed more animated when male staff members entered his room, so male transport orderlies were involved in his care. All providers were asked to remove laboratory coats before entering M.J.'s room because they seemed to increase his agitation. A list of M.J.'s likes and dislikes was kept on his bedside chart.

## How can pain and anxiety be assessed in a nonverbal patient with autism?

McCaffrey and Pasero (1999) stated that pain is what the person says it is and occurs when the person says it occurs. The simple task of assessing pain and anxiety in a cognitively impaired, nonverbal patient is difficult. Behavioral observation-based assessment is the best practice for patients with cognitive impairments who cannot verbalize pain (Buffum, Hutt, Chang, Craine, & Snow, 2007). The Critical Care Pain Observational Tool is one of the first observational pain assessment tools to demonstrate acceptable validity and reliability in intubated patients (Pun & Dunn, 2007). The scale measures behaviors, such as facial expressions, body movements, muscle tension, and compliance with the ventilator, and scores each section from 0–2. Total scores range from 0–8 with higher scores indicating greater pain. The scale was used to assess M.J.'s pain while he was intubated. The staff used the Adult Non-Verbal Pain Scale (Rothman, 2006) after extubation to assess pain and anxiety. The scale, also behavior-observational based, measures facial expression, activity, guarding as a defense mechanism to prevent movement of a painful or injured body part, vital signs, and diaphoresis. The scale is a consistent and valid tool for assessment of pain in critically ill, nonverbal adults (Odhner, Wegman, Freeland, Steinmartz, & Ing, 2004). Additionally, parents and other caregivers should be encouraged to participate in the assessment. "The best pain assessment by proxy is that provided by caregivers or family members who know the patient. Only they can identify changes from a patient's baseline behavior that may signify pain and anxiety" (Wick, 2007, p. 4). Some uncharacteristic behaviors that were noted by family as pain indicators included facial grimacing, moaning, splinting, shaking, and hunched walking.

Matching medication to pain level is important for any patient, regardless of cognition (Buffum et al., 2007). Short-acting opioids should be used so that any changes in mental status can be evaluated without their influence (Herr et al., 2006). M.J.'s healthcare team used patient-controlled epidural analgesia with fentanyl and bupivacaine, followed by a patient-controlled analgesia IV of morphine sulfate. The nurses and family used this combination by proxy, maintaining a basal rate that was increased when M.J. was having breakthrough pain.

Sedation primarily is used in the intensive care unit to relieve anxiety and agitation (Pun & Dunn, 2007). Patients with ASD may be hypersensitive to sound, touch, pain, and lights, which all are known anxiety stimulants in the intensive care unit (National Autistic Society, 1990). A continuous infusion of propofol, a short-acting hypnotic agent, was used to reduce M.J.'s anxiety while he was intubated

(Gabriel & Gluck, 1973). However, after extubation, M.J. displayed anxious and agitated behaviors (e.g., pushing, acting out, hitting, wild movements of extremities). To calm him, lorazepam, a short-acting benzodiazepine, was administered because of its minimal effects on the respiratory and cardiovascular systems.

Many nonpharmacologic interventions were used to decrease the use of sedative. Heat, cold, massage, relaxation, and distraction techniques do not require significant cognitive ability and may be helpful in anxiety relief and pain management with low risk of adverse effects (Buffum et al., 2007). M.J. liked warm baths, and taking walks, watching movies, and listening to music were helpful distraction techniques. Marwick (1996) supported the use of music therapy in patients with autism, stating that it can have a positive effect because their brains respond to music more readily than mechanical speech. M.J. responded positively to music tapes from home.

## What are potential postoperative complications for which patients with autism would be at increased risk, and how can they be prevented?

Management of patients undergoing retroperitoneal lymph node dissection after chemotherapy differs from that of patients undergoing the surgery prior to chemotherapy. The latter usually are more physically fit, and the primary dissection usually is smaller. Superficial wound infection is the most frequent complication, followed by small bowel obstruction and atelectasis (Baniel, Foster, Rowland, Bihrie, & Donahue, 1994). Pulmonary complications are the most common cause of morbidity in the postchemotherapy group, particularly if bleomycin was part of the chemotherapy regimen. Chylous ascites commonly form after surgery when venacavotomy is performed (Baniel et al., 1995). Decreased nutritional reserves may put the patient at increased risk for complications. M.J. developed a chylous leak and pancreatitis that were managed conservatively with total parenteral nutrition.

Preventing complications after surgery is difficult in a patient with autism because of the inherent language disorders, ritualistic behaviors, impaired understanding and socialization, as well as lack of appropriate fear response to danger and unusual reactions to the way foods taste and smell (APA, 2000; Augustyn, 2007). Patients may become uncooperative or combative if they do not understand the need for help. The family reported that M.J. reacted in this manner during a previous hospitalization. As a result, physicians kept M.J. sedated and intubated longer than usual to protect him from injuring himself. This prolonged period of sedation and intubation increased M.J.'s risk of developing pulmonary complications. He was placed in a bed that provided automatic vibration, percussion, and rotation. Pulmonary toilet was encouraged after extubation by allowing M.J. to blow into party favors and

by having him wear a specialized vest that bombards the chest wall with high-frequency oscillations. Despite these measures, M.J. still developed aspiration pneumonia.

The nurses were vigilant in assessing for wound infections and changes in bowel function. Family members were instructed on the signs and symptoms and were helpful in obtaining M.J.'s cooperation when physical assessment was necessary, as well as monitoring M.J. to prevent injury.

## How are patients with autism and family caregivers prepared for discharge after surgery?

A literature search failed to reveal evidence-based practice specifically pertaining to postoperative discharge planning for an individual with autism. Black and Hyde (2004) reiterated the challenges faced in finding information for cognitively impaired patients with cancer. In M.J.'s case, the cancer center extrapolated discharge instructions from those for older adult patients and the cognitively impaired. Bull, Hansen, and Gross's (2000) Professional-Patient Partnership Model, stressing patient participation, family involvement, and interdisciplinary collaboration to achieve a successful discharge, was followed. Positive outcomes include caregivers who are equipped to handle care; have increased information about care management, health status, and available services; and report more satisfaction with care. In addition, patients spend fewer days in the hospital if readmission is required (Bull et al.; Walker, Hogstel, & Curry, 2007).

The staff consulted with case managers and tailored M.J.'s discharge planning to his specific needs. The healthcare team discussed discharge instructions with family members throughout M.J.'s hospital stay and assessed what information they needed to know related to his home care. The family received extensive training in the care of the peripherally inserted central catheter line, NPO status, activity level, care of the abdominal drain, incision assessment, and medications. Home physical therapy and occupational therapy services were arranged. A referral to visiting nurses was made for care of M.J.'s central catheter line and total parenteral nutrition infusions. Medical equipment (IV pump and bedside commode) were ordered. Follow-up doctor appointments were scheduled. M.J.'s family, particularly his mother, understood and was comfortable with the discharge plans.

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## Clinical Highlights: Autism Spectrum Disorder

### Definition

Autism spectrum disorders (ASDs) or pervasive developmental disorders (PDDs) are terms for a continuum of neurodevelopmental disorders, all of which are characterized by social (thinking, feeling, and relating to others), communication (verbal and nonverbal), and behavior (rigid, repetitive, and stereotyped) impairments. The disorders usually are diagnosed in early childhood. Autistic disorder (classic autism, early infantile autism, or Kanner disorder) is the most severe form, followed by PDD, PDD not otherwise specified (PDD-NOS), and Asperger syndrome, a form of high-functioning autism. Rett syndrome and childhood disintegrative disorder are two rare but severe disorders also classified as PDDs (Augustyn, 2007; Strock, 2004).

### Prevalence

The Centers for Disease Control and Prevention ([CDC], 2007) reported an ASD prevalence rate of 1 in 150 eight-year-old children in many areas of the United States. Based on the data, an estimated 560,000

individuals, aged 0–21, have ASD (CDC). Researchers do not know whether the data represent a true increase in incidence or a result of changes in diagnostic criteria. Comparable rates are seen in African American and Caucasian children (Yeargin-Allsopp et al., 2003). Boys have a higher incidence of autism, with a ratio of 3.5–4 males:1 female (Volmar, Klin, & Schultz, 2005; Yeargin-Allsopp et al.). The gender ratio is greater when mental retardation is not a factor (6 males:1 female) and lower when patients are severely mentally retarded (1.5 males:1 female) (Volmar et al.).

### Etiology

Initial speculation that emotional factors (e.g., a cold or indifferent mother can cause autism) have not been borne out (American Psychiatric Association [APA], 2000; Volmar et al., 2005). Current evidence points to one or more factors acting on the central nervous system, which leads to altered brain development. One theory involves epigenetics, which is a change in gene function without a change in DNA; the changed gene then affects the

expression of other genes. Environmental factors such as toxic exposures in utero could cause this. Evidence for a genetic factor includes the increased risk (by 2%–7%) among siblings (APA; Volmar et al.); a 90% chance that if one identical twin has ASD, the other also will (Asher, 2006); and the increased risk for other developmental difficulties among affected siblings (APA; Augustyn, 2007; Volmar et al.). Scientists at the National Institutes of Health identified a gene (the *c* version of the *MET* gene, a tyrosine kinase growth factor receptor) believed to exert a strong effect on the development of ASD (Asher). If a child inherits two copies of this version, the chance of developing ASD is more than doubled (Asher). The Autism Genome Project Consortium (2007) recently published data implicating variations in chromosome 11p12–p13 and neurexins, glutamate-related genes, as possible contributors to the etiology of ASDs. Autopsies and imaging studies have suggested brain abnormalities that may play a role. Autism increases overall brain size

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2%–10% (APA; Augustyn; Volmar et al.); about a third of children with ASD have increased levels of peripheral serotonin (APA; Augustyn; Volmar et al.); and 10%–83% have abnormal electroencephalograms in the absence of a clinical seizure disorder (APA; Volmar et al.). The development of epilepsy also occurs in 10%–35% of children with autism by young adulthood, particularly in lower functioning individuals (Volmar et al.). Controversy exists regarding the hypothesis that vaccines, particularly measles-mumps-rubella and those containing thimerosal (a mercury preservative), are a causative factor. The Institute of Medicine's (2004) immunization safety review found no evidence of a causal relationship.

### Diagnosis

By definition, the onset of autism occurs before the age of three (APA, 2000). No test can diagnose this disorder; it usually requires clinical observations, patient and family interviews, developmental histories, psychological testing, and speech and language assessments.

### Common Clinical Features

Social interaction impairment may be manifested by such behaviors as the inability to use nonverbal communication or to develop peer relationships. Communication impairment may be manifested by delayed or lack of speech development or, if the person can speak, the inability to have a conversation. Restricted or stereotyped patterns of behavior or interests may be manifested by persistent fixation with objects or interests, inflexible adherence to nonfunctional routines, or repetitive motor mannerisms. About 70% of individuals with autism also have some degree of mental retardation (Volmar et al., 2005). Autistic individuals may have highly developed skills or behavioral issues, such as hyperactivity, lack of fear in response to danger, tendency to injure themselves, eating and sleeping difficulties, and odd responses to sensory stimuli; and minor physical abnormalities, such as ear malformations. Common comorbidities include seizures, fragile X syndrome, tuberous sclerosis, and fetal alcohol syndrome (APA, 2000; Augustyn, 2007; Volmar et al.)

### Differential Diagnosis

ASDs are differentiated by the age of onset. Individuals with childhood degenerative disorder develop normally for the first two years; Rett disorder for 5–30 months; and Asperger syndrome for three years before experiencing significant regression. Disorders classified as PDD-NOS vary in the age of onset. Rett disorder is more common in females, whereas the others are more

common in males. Children with childhood degenerative disorder and Rett disorder usually have severe mental retardation. Seizures are uncommon with Asperger syndrome or PDD-NOS, frequent with Rett disorder, and common in autistic disorder and childhood degenerative disease (APA, 2000; Volmar et al., 2005).

### Treatment

Treating a child with autism must be individualized. Early intervention is important, and the chosen program should be highly structured and specialized. Goals should include reduction of disruptive behaviors and promotion of learning, particularly in language acquisition and self-help skills. Programs should include some combination of speech-language therapy, behavior-modification techniques, and psychotherapy for those with anxiety and depression (Strock, 2004; Volmar et al., 2005). A public school system's responsibility ends when the child is 22 years old. The family then must find programs and make living arrangements that meet the individual's needs. Services for adults with autism vary from state to state. Most have a department of developmental disabilities and a department of mental health that determine who is eligible for services. In addition, each state receives federal money under the Rehabilitation Act (U.S. Department of Education, 2004) to be used for vocational rehabilitation. Asperger Foundation International ([www.aspfi.org](http://www.aspfi.org)) has a list of available services in the United States.

Medications may be used to treat behavioral issues. The selective serotonin uptake inhibitors are used most often to treat anxiety, depression, or obsessive-compulsive disorder in adults with autism. They usually are chosen because of the increased serotonin levels seen in many patients. They have been proven superior to placebo in relieving symptoms such as repetitive behaviors and aggression. McDougle et al. (1998) found that risperidone, an antipsychotic medication, reduced repetitive behavior, aggression, anxiety, depression, irritability, and overall behavioral symptoms of autism in 57% of the 14 patients they treated. Anticonvulsants are used to treat seizure disorders, and stimulants such as methylphenidate may help decrease impulsivity and hyperactivity (Strock, 2004; Volmar et al., 2005). Caretakers often are interested in alternative treatments to alleviate the behavioral symptoms of autism, especially diet and vitamin therapy. It is important to recognize that no controlled studies support claims for a particular diet or vitamin (Volmar et al.).

### Prognosis

Modest improvement in the core symptoms (communication, reciprocal social inter-

action, and restricted and repetitive behaviors and interests) occurs in some individuals from childhood to adolescence to adulthood. However, this rarely leads to normal functioning, and improvement is not seen for all behaviors. Some individuals actually show a worsening of symptoms, particularly those who were low functioning as children or who develop seizures. IQ is probably the strongest predictor of outcome (APA, 2000; Seltzer, Shattuck, Abbeduto, & Greenberg, 2004). Howlin, Goode, Hutton, and Rutter (2004) found that adults who had a childhood IQ of 70 or higher were more likely to live independently. Adults with early language skills were more likely to have relatively independent functioning and near-normal social relationships (Seltzer et al.). A child whose caregivers were empathetic, let the child lead interactions, named objects for the child, commented on the child's activities, and engaged in play time developed better verbal skills (Seltzer et al.). Approximately 60% of adults with autism live with their parents, and most of those living apart require considerable support from family members or social services (Howlin, 2003). About 15%–25% of adults with autism are able to live independently, hold competitive jobs, and maintain social relationships (Seltzer et al.); however, even the highest functioning adults characteristically continue to exhibit some difficulty with social interaction and communication, and have very limited interests and activities (APA, 2000).

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