Who Are Higher Functioning Young Adults with Autism?

Ann Fullerton

[With thanks to Steve Edelson, Autism Research Institute, San Diego, California, who provided information on the sensory realm.]

This chapter explores the characteristics and experiences of higher functioning persons with autism. We have learned important new information about autism in recent years, thanks in part to the insights shared by persons with autism themselves. A number of these individuals have chosen to describe themselves as "higher functioning persons with autism."

The term *higher functioning* refers to the cognitive ability of the individual. Higher functioning persons with autism have mental abilities in the average to above-average range. Within the higher functioning group, however, there is a wide range in the severity of autistic characteristics. Thus, higher functioning persons with autism may have mild (much like a learning disability), moderate, or severe autism.

A GENERAL DEFINITION OF HIGHER FUNCTIONING AUTISM

The Autism Society of America defines autism as "the result of a neurological disorder that affects functioning of the brain. . . " (Autism Society of America, 1993, p. 3). Donna Williams, a young woman with autism, puts it another way: "Autism is just an information processing problem that controls who I appear to be . . ." (Williams, 1994, p. 238).

Autism is a lifelong developmental disability that typically appears in the first three years of life (Autism Society of America, 1993). Autism is rare, occurring in about 15 of every 10,000 births, and is four times more common in boys than in girls. It is estimated that 25% (Dawson & Castelloe, 1992) to 50% of persons with autism are higher functioning, but at this time such estimates are not based on agreed-upon criteria.

Autism can occur by itself or in combination with other disorders. Autism is not a form of mental retardation or a mental disorder, but it is sometimes misdiagnosed as such, resulting in inappropriate and ineffective treatment. At the present time we do not know what causes autism, but it appears that both genetic factors and neurological damage due to prenatal or birth injury may be involved. Autism is not a result of parenting or emotional trauma (Autism Society of America, 1993).

Some of the behavioral characteristics of higher functioning persons with autism are described below. Some, but not all of these characteristics, might be present in a particular individual. Moreover, these characteristics vary widely in intensity. Each person with autism has a unique blend of strengths and challenges.

BEHAVIORAL CHARACTERISTICS OF AUTISM

- *Differences in the rate of appearance of physical, social, and language skills.* Children with

autism may show a scattering of skills and may skip normal developmental steps. A child may develop fine motor skills (e.g., puzzle solving, holding a pencil) before gross motor skills (climbing, running) or vice versa. A child may have a significant delay in learning cause and effect. A student may have exceptional skills in one area of interest. A student may have good word reading, spelling, and math, music, or artistic skills but have difficulty with reading comprehension, story problems, or other cognitive tasks that require creative thinking, cause/effect relationships, judgments, or use of information unrelated to their actual life experience (Janzen, 1986a).

- *Differences in responses to sensory stimuli.* "Any one or a combination of senses or responses are affected: sight, hearing, touch, balance, smell, taste, reaction to pain, and the way a person holds his or her body . . ." (Autism Society of America, 1993, p. 3). Persons with autism may be hyper- or hyposensitive to sensory stimuli and have unusual responses to visual, auditory, or tactile stimuli. They may have difficulty screening out sensory input. They may engage in subtle and not so subtle forms of repetitive behavior (Janzen, 1986a). These may be a release of tension, a response to stress, a way to focus, or a way to control sensory input.
- *Differences in the development of communication.* Persons with autism may have difficulty generating language for fluent, interactive communication. They may have difficulty coordinating the nonverbal behaviors associated with social interaction. Their understanding and use of language may be concrete and literal. They may be confused by words and expressions that depend on the context for meaning (e.g., jokes, sarcasm). They may have difficulty monitoring the reactions of a conversational partner, staying on the topic, and maintaining the conversation (Janzen, 1986a).
- *Differences in ways of relating to people, objects, and events* (Autism Society of America, 1993). Persons with autism may focus on a small detail and have trouble shifting their focus to more critical elements or information. They may have difficulty sequencing past events yet remember certain events accurately and in great detail. They may have fairly restricted interests. They may be disorganized in time and space. They may develop specific routines for carrying out everyday tasks. They may have difficulty with changes in activities or routines (Janzen, 1993).

As noted earlier, the severity of these characteristics ranges widely in higher functioning persons with autism.

Asperger's syndrome, first described by Asperger in 1994, is a separate developmental disorder that is closely related to higher functioning autism (American Psychiatric Association, 1993). Persons with Asperger's syndrome display one or two of the characteristics described above in milder forms (Dawson & Castelloe, 1992). For example, an individual may develop highly grammatical speech and extensive vocabularies at a young age and at the same time have unusual use of voice and affect as well as difficulty with turn taking or perspective taking in conversation. Persons with Asperger's syndrome may also have learning disabilities in reading, writing, or mathematics. Most of these individuals succeed in academics in school or with the cognitive aspects of their work. However, most have persistent difficulty in understanding social situations, find them challenging and/or uncomfortable (Wing, 1992), and are aware of at least some of their difficulties in the social area.

THREE REALMS OF EXPERIENCE: SENSORY, COGNITIVE, AND SOCIAL

In attempting to describe autism, it is useful to consider the views of family members, teachers, researchers, and especially higher functioning persons with autism themselves. What is often said is that persons with autism process information differently. We will examine this difference in the realms of sensory, cognitive, and social experience. Each of these realms of experience is affected by autism (see Figure 1.1).

For example, in the sensory realm, persons with autism may report sensory perceptions that

FIGURE 1.1. Three Realms of Experience. In this drawing, some of the sensory, cognitive, and social experiences of persons with autism are depicted. In the sensory realm, persons may experience hypersensitive hearing or visual-perceptual challenges. In the cognitive realm, an individual may have a strong visual memory and difficulty organizing abstract information. In the social realm, persons may have difficulty recognizing visual and nonverbal social cues and rules.

differ from those of persons without autism. In the cognitive realm, persons with autism may have excellent memories for factual information but may be challenged by everyday problem solving. In the social realm, the person with autism may have difficulty perceiving what most people would consider to be socially relevant in a situation.

In life, the sensory, cognitive, and social aspects of an experience overlap and influence each other. The same is true here. For example, one's sensory experiences or one's cognitive style can affect one's ability to participate in social situations.

The Sensory Realm

The sensory realm involves how one perceives and learns about the world through one's sensory systems (Figure 1.2). Researchers, parents, and persons with autism have all reported that some persons with autism have differences in their sensory systems. One learns about the world through one's senses. Thus, a different sensory system could result in a different view of the world.

Delacato (1974) was one of the first researchers to speculate that the senses of some persons with autism may be hypersensitive, hyposensitive, or contain white noise. More than one sense may be affected, and both hyper- and hyposensitivities may be experienced at the same time. Some persons with autism report that when there is too much sensory stimulation, they experience sensory overload (Grandin, 1992) and a temporary shutdown of, for example, vision or hearing (Williams, 1994). Another experience that is described is an inability to focus on a specific sensory input if there is too much background sensory input present (e.g., using the phone in an airport) (Grandin & Scariano, 1986). A

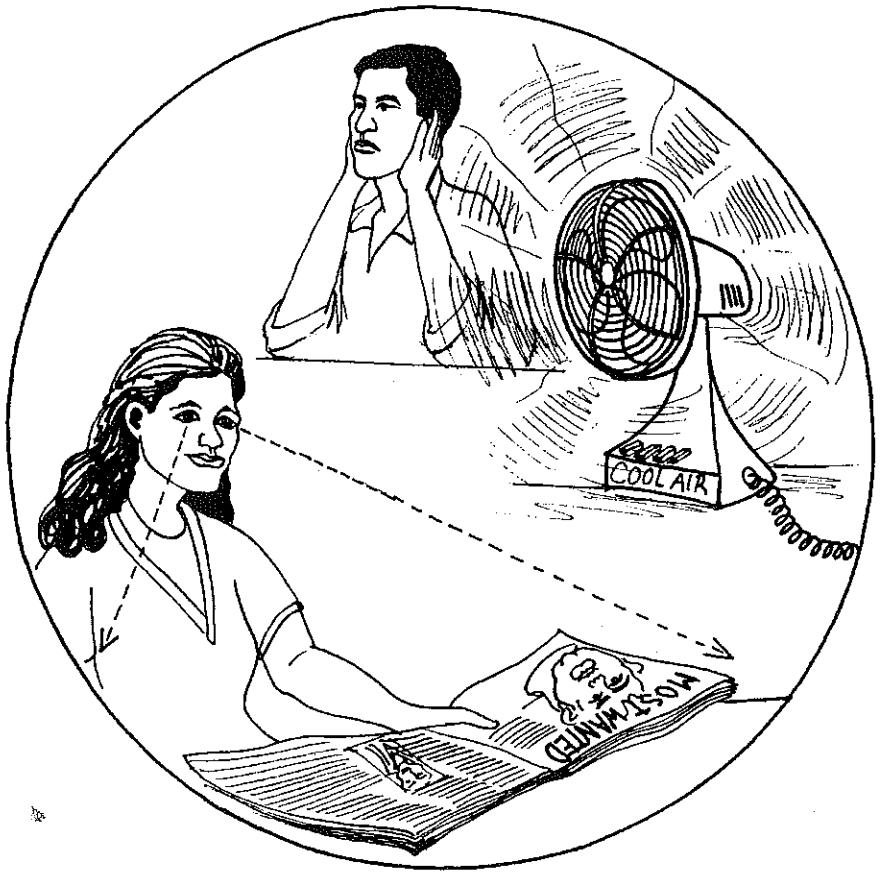

FIGURE 1.2. The Sensory Realm. In this realm, persons may experience hypersensitive hearing or visual-perceptual challenges.

related experience of some persons with autism is being unable to shift one's attention from one sensory modality to another (e.g., from visual to auditory input) (Grandin, 1992; Williams, 1994). Studies have shown that some persons with autism have difficulty shifting between different cues in one sensory modality (Wainwright-Sharp & Bryson, 1993), and with shifting attention between sensory modalities (Courchesne, Akshoomoff, & Ciesielski, 1990).

Differences in all the various sensory systems, including the auditory, olfactory, tactile, gustatory, vestibular, and visual systems, have been reported. A brief review of each system is described below. Some but by no means all persons with autism have had these experiences. Some persons report that their sensory sensitivities decreased with age and they suspect that this occurred because they learned to adapt to or cope with the sensitivity. For others, no change occurred with age; and as adults they have made lifestyle choices in order to reduce, for example, the level of auditory stimulation in their home (personal communication, 1992–1993).

Auditory. Common auditory problems are hyperacute hearing, painful hearing, and a constant noise (or tinnitus) interfering with hearing. Hyperacute hearing was the main focus of a book titled *Sound of a Miracle* (Stehli, 1991) in which a mother described her daughter's hypersensitivity to sounds. The daughter, Georgie, could hear some sounds that others could not hear (e.g., water rushing through pipes in the walls) and heard some sounds much louder than others (e.g., rain on the pavement sounded like machine guns). Other parents have reported similar stories, such as their children hearing the neighbors talk in an adjacent house and hearing sirens and airplanes in the distance before others. Collet and his colleagues (1993) recently documented abnormal neurological suppression of auditory stimulation in the brainstem of autistic individuals. They suggested that this lack of suppression may be responsible for sounds being perceived much louder than normal.

Painful hearing also occurs in many people with autism. A survey of over 12,000 parents of autistic children indicated that approximately 40% of their children exhibit some form of painful hearing (Rimland, 1990). Temple Grandin describes her hearing:

> My hearing is like having a hearing aid with the volume control stuck on "super loud." It is like an open microphone that picks up everything. I have two choices; turn the mike on and get deluged with sound, or shut it off. Mother reported that sometimes I acted like I was deaf. Hearing tests indicated that my hearing was normal. I can't modulate incoming auditory stimulation. . . . I still dislike places with confusing noise, such as shopping malls. High-pitched continuous noises such as bathroom vent fans or hair dryers are annoying. I can shut down my hearing and withdraw from most noise, but certain frequencies cannot be shut out. It is impossible for an autistic child to concentrate in a classroom if he is bombarded with noises that blast through his brain like a jet engine . . . . (Grandin, 1992, p. 107)

The notion that some autistic individuals' auditory systems contain noise (tinnitus) was first introduced by Delacato (1974). Although this phenomenon has not been empirically documented, there have been numerous self-reports by autistic children and adults who claim to hear sounds similar to white noise, such as buzzing sounds and motorcycle sounds in their ears (personal communications, 1991–1993). Some individuals have reported a disappearance of these sounds after receiving auditory integration training, a relatively new sound-sensitivity intervention for these individuals (Berard, 1993).

Olfactory. Some persons with autism appear to have hyper- and hyposensitive olfactory systems. Those individuals who are hypersen-

sitive have difficulty with strong perfumes and deodorants, minor house odors, and odorous foods, whereas those individuals who are hyposensitive crave strong odors, such as gasoline. As of this writing, there have not been any studies that have empirically examined this sensory problem.

Tactile. Through the tactile sense, or sense of touch, one can distinguish between a light touch on the skin, different textures, or deep pressure. Some persons with autism have difficulty adjusting to certain tactile sensations. Combinations of hyper- and hyposensitivities are also experienced.

Temple Grandin (1992) reports that it is very hard to adapt to the feel and fit of different clothes. Whereas it might take a person without autism a few minutes, it takes her three to four days. Persons with autism have reported that as children, physical contact from others such as a light touch or hug was physically unpleasant, and so they avoided it (personal communication, 1991–1993). It has been observed that some infants with autism arch their back when they are picked up. It may be that this reaction is based on tactile hypersensitivity and sensory "overload."

Whereas lighter tactile stimulation may be aversive, deeper pressure, when it can be controlled by the individual, may be pleasant and calming. Temple Grandin (1992) describes her experiences. She states that she craved pressure stimulation:

> . . . it was an approach-avoid situation. I wanted to feel the good feeling of being hugged, but when people hugged me the stimuli washed over me like a tidal wave. When I was 5 years old, I used to daydream about a mechanical device I could get into that would apply comforting pressure. Being able to control the device was very important. I had to be able to stop the stimulation when it became too intense. When people hugged me, I stiffened and pulled away to avoid the all-engulfing tidal wave of stimulation. . . . (p. 108)

At age 18, Dr. Grandin designed and built a squeezing machine. A person using the machine could control the amount and duration of pressure applied to the sides of his or her body by pulling a lever (see Grandin and Scariano, 1986, for a description). The deep pressure made possible by the machine can have a very calming effect. Occupational therapists have used Temple's machine with children with autism (Grandin, 1992), as well as other strategies for sensory integration and desensitization (Ayres, 1979).

Gustatory. As is the case with the sense of smell, there is little research but many reports of a unique sense of taste among individuals with autism. Those with hypertaste tend to avoid eating foods with strong flavors and often eat only bland foods. A person may have great difficulty taking medications and vitamins because of their taste.

Vestibular. The vestibular sensory system is connected to the inner ear and provides the body with a sense of balance. A great deal of research has been conducted on the vestibular sense in autism (see Freeman, Frankel, & Ritvo, 1976; Ornitz, 1985). An underaroused vestibular system is considered the primary reason for the rocking behavior of some persons with autism. As adults, many of these individuals actively seek intense vestibular stimulation, such as roller coasters and free-fall rides at amusement parks. In contrast, some people with a hypersensitive vestibular system tend to resist many forms of motion, such as swinging.

Visual. There have been many reports of unusual visual processing in persons with autism. These include difficulty with eye contact, overreliance on peripheral vision, sensitivity to light and color, tunnel vision, and differences in how temporal/spatial relationships are visually perceived.

Some persons with autism are observed to avoid eye contact (Rimland, 1964; Slavik, 1983; Volkmar & Mayes, 1990). Wulf (1994) actually

reports that she experiences pain when making prolonged eye contact with other people. By avoiding direct eye contact with others, these individuals rely on observing others using peripheral vision, another characteristic of autism. One autistic man, Gene M., was asked why he looked at people using his peripheral vision, and he replied that "it is like looking through jelly" when looking directly at a person (Marcus, 1992). There is indirect evidence to support the possibility of a dysfunctional visual system in some persons with autism. Creel, Crandell, Pingree, and Ritvo (1989) found abnormal electrical activity in the retina of nearly half of 22 autistic individuals.

Visual hypersensitivity to light and to specific colors has also been observed. Some persons with autism appear to be almost blinded by sunlight and must wear sunglasses in order to see in daylight. There are also reports of children covering their eyes when people wear brightly colored clothing. A number of persons with autism are highly skilled visual artists.

Some persons with autism tend to focus on a specific feature or dimension of an object and have difficulty attending to other nearby features (Lovaas, Koegel, & Schriebman, 1979; Rincover, Feldman, & Eason, 1986). Such "tunnel vision" may limit one's ability to take notice of visual stimuli present in one's environment (Rincover & Ducharme, 1986; Rincover, Feldman, & Eason, 1986). Donna Williams (1992) wrote that she appeared to stare into space as a child, when in actuality she was focusing on the colors emitted from dust particles. In visual perception experiments, some higher functioning persons with autism may miss or respond more slowly to rapidly changing and novel visual cues than persons without autism (Wainwright-Sharp & Bryson, 1993).

Melvin Kaplan has studied the visual systems of autistic individuals for many years and has suggested that persons with autism as well as other individuals with neurological problems have difficulty processing temporal/spatial relationships. Such visual perception problems can lead to difficulties moving in and interacting with the physical environment. Kaplan suggests that the characteristics of some children with autism, such as toe walking, or unusual posture or balance, can be explained by differences in the visual system (Kaplan, in preparation).

Recently, Donna Williams (1993) has described the visual perception she experiences. She reports that scenes and objects are fragmented and she cannot distinguish between the foreground and background. Donna was not aware that she saw things differently until she tried corrective lenses. According to her, the lenses allowed her to look directly at an object, scene, or person and see the parts and whole as one, integrated perception. Looking at her friend Paul, she reports:

> . . . Paul's face was joined together. His eyes and nose and mouth and chin were all held together with equal impact in a single context. Then I noticed that his neck and shoulders and torso and legs were also joined, not bit by bit as my eyes moved along, but as a whole picture, like captured by a camera. Paul was joined together and he looked great. (Williams, 1994, pp. 7–8)

Summary of the Sensory Realm. At the present time it is not clear what neurological differences underlie these sensory experiences. The source of this difference does not seem to lie in the sensory organs (eyes, ears); these appear to be intact in persons with autism (Hermelin & O'Connor, 1970). Instead, recent studies have suggested that portions of the brain that may regulate sensory input may be different in persons with autism (Bauman & Kemper, 1994).

In Figure 1.3, some of the sensory experiences that different persons with autism have reported are illustrated. In the innermost ring is a person. The next ring depicts various sensory sensitivities. The next ring illustrates what the person might think or wish he or she could do in response to these sensory experiences. The outermost ring portrays what the person chooses to do instead in order to cope with these experiences in a social world.

FIGURE 1.3. Some of the sensory experiences of some persons with autism.

The Cognitive Realm

The cognitive realm includes attending, learning, remembering, and problem solving. The preceding description of the sensory realm indicated that many persons with autism perceive and process sensory information differently. What this means is that the information or "raw material" one has available to think about is different. If one takes in different information than others, then it follows that one will reach different conclusions. In highly complex ways our sensory processes and our cognitive processes are intertwined. Researchers are just beginning to explore the implications of the sensory system of people with autism on their cognitive development.

Cognitive Style. Apart from these sensory-cognitive relationships, researchers have also noted that individuals with autism have a different cognitive style. In this section we turn to accounts and descriptions of this particular style (see Figure 1.4). This cognitive

FIGURE 1.4. The Cognitive Realm. In the cognitive realm, an individual may have a strong visual memory and difficulty organizing abstract information.

style is described as one in which information is taken in with little analysis or integration (Prizant 1983; Frith, 1989; Janzen, 1993). All of the aspects of an experience are taken in and may be remembered with equal significance. The person with autism has difficulty extracting from the situation what others would see as most relevant, functional, or meaningful.

Jan Janzen (in preparation) has used the analogy of a video camera to describe what it would be like to take everything in.[1] Think for a moment of the brain as a super recording device that takes in every sight, sound, touch, taste, and odor, in minute detail. The person with autism has difficulty controlling the device to

> analyze or "edit" the tape to screen out irrelevant material, it is all stored randomly and unintegrated into single separate units. . . . If the camera is on, everything goes in. If it is off, nothing goes in. Sometimes the camera is turned on and off quickly, so the event is stored as a short unit (a snapshot). Other units are longer. . . . with no relationship to the actual beginning or end of the event. Sometimes the lens is focused on something of particular interest to the individual while relevant information is described or modeled by the teacher in a different

[1]This analogy is expanded in the book: Janzen, J. E. (in preparation). *Understanding the nature of autism: Strategies for parents and teachers*, Tucson, AZ: Communication Therapy Skill Builders.

> part of the room. . . . Whatever is recorded, is stored. It is easy to see why the world is so confusing for them. . . . (Janzen, 1993, p. 8)

In this analogy, Janzen has described how the person with autism may attend to and remember information.

Once information is received, how then is it used to solve problems? In order to explore this question, Uta Frith (1989) has compared the way children with and without autism solve cognitive tasks. She suggests that persons without autism ". . . have a built-in propensity to form coherence over as wide a range of stimuli as possible or as wide a range of contexts as possible . . . " (Frith, 1989, p. 100). Persons with autism, however, may not perceive or use the overall context, meaning, or structure available to solve a cognitive task.

Sometimes, not seeing the overall context can be useful. For example, if asked to find a triangle shape hidden in a picture of a baby buggy, children with autism may find the hidden shape more easily than children without autism (Frith, 1989). Some children with autism can memorize a meaningful sentence and a radom list of words equally well.

Children *without* autism, however, find it harder to remember random list of words than meaningful sentences (Frith, 1989). These findings suggest that the child with autism may not perceive or use the overall meaning to be found in a problem in order to solve the problem (Frith, 1989). The cognitive style described by Janzen (in preparation) and Frith (1989) is reflected in how persons with autism attend, learn, remember, and solve problems.

Attending. Persons with autism are able to attend and to sustain their attention, but they may have difficulty controlling their attention. It may be hard to activate their attention, to stay focused, or to flexibly shift their attention when it is adaptive to do so (Rumsey, 1992). For example, some higher functioning persons with autism may find it difficult to rapidly scan stimulus materials and make a quick response (Rumsey, 1992). Higher functioning persons with autism can also have difficulty when a task requires them to shift their attention in midstream (Rumsey, 1992).

On the other hand, some higher functioning persons with autism do very well on tasks that require one to stay focused on and manipulate numerical information (Rumsey & Hamburger, 1988). Some may also perform well on other tasks that require sustained attention. Thus, persons with autism have strengths and also face challenges in the act of attending.

Memory and Learning. Many persons with autism have excellent long-term memories and can recall in minute detail events that occurred years before. This has been considered to be a form of eidetic memory, in which all aspects of an event are stored and can later be fully retrieved. Often higher functioning persons with autism have excellent rote memories and learn new factual, concrete information accurately after a single presentation. However, they may not attach meaning to the information (Janzen, 1986b).

When remembering larger amounts of information, such as a paragraph, persons with autism may have difficulty immediately recalling the paragraph but do benefit from rehearsal such that the more they repeat information the better they can remember it at a later time (Rumsey, 1992). This suggests that they are encoding the words at a literal level, whereas persons without autism use associative or semantic features in order to remember in both the short and the long run (Rumsey, 1992). Thus, "rote memory, unaltered by active encoding or deeper levels of processing may be characteristic of autism . . ." (Rumsey, 1992, p. 47).

How is this different from the way the person without autism remembers? Cognitive theorists speculate that when one remembers something, one encodes it in some way. Encoding means that the new information is organized in ways that are meaningful to the person and tied to prior knowledge, thereby making it easier to retrieve later when needed.

Researchers believe that when persons without autism store information, it is associated with a social context and in a temporal relation-

ship to other events. Because one makes meaning of something in order to remember it, one selectively remembers only parts of the event. Persons with autism may "encode" differently. One man with autism speculated, ". . . I think most normal people have a memory that is like a continuum. Mine is just like up here. I can remember something but I don't remember what came before or after . . ." (McDonnell, 1991). Donna Williams describes her memory in discussing a conversation with her therapist/teacher:

> He thought he could help me find different ways to tackle various problem situations. I couldn't really see how he could help though. I would learn how to tackle a given situation in one context but be lost when confronted by the same situation in another context. Things just didn't translate. If I learned something while I was standing with a woman in the kitchen and it was summer and it was daytime, the lesson wouldn't be triggered in a similar situation if I was standing with a man in another room and it was winter and it was nighttime. Things were stored but the compulsive over-categorization of them was so refined that events had to be close to identical to be considered comparable. . . . (Williams, 1994, pp. 64–65)

Problem Solving. Some higher functioning persons with autism have difficulty with a wide range of problem solving tasks. They may understand the language involved in the problem and have excellent visioperceptual skills but run into difficulty because they don't integrate information to draw inferences (Rumsey & Hamburger, 1988). On other problem solving tasks, they may repeat the same errors and have difficulty learning from experience (Hoffmann & Prior, 1982). These challenges with problem solving tasks are less evident in persons with Asperger's syndrome (Rumsey, 1992).

In everyday life we often need to problem solve. In the following passage a woman with autism describes her experience in a job indexing newspaper articles. She describes two challenges that she faced: (1) knowing that she needed to organize information but not having the social knowledge with which to make judgments and (2) having difficulty coordinating the multiple aspects of the task.

> I started indexing the Chicago Times at home on a part-time basis. However, I was unable to deal with the subtle nuances of the work: Which subject heading should I use? Should I index this editorial? I could not figure out the answers. This was a problem I had had in other jobs as well. I could not generalize from one situation to another and could not deal with the many complexities involved in any one task—a typical problem in autistic people. I was let go from this job primarily for that reason, although my supervisor greatly admired my work and wanted me to continue. . . . (Carpenter, 1992, p. 292)

Visual Thinking. Some persons with autism describe themselves and are observed to be strong visual thinkers. They have excellent ability to remember and retrieve visual images. Some young adults with autism have become aware that they cannot remember long strings of auditory information. When too much and too long a string of verbal information comes their way, they "shut down," but when the same information is presented visually in pictures and words, they know what to do. These individuals ask others to write down the steps in a task for them so that they can learn the task (Williams, 1992; Grandin, 1992).

Temple Grandin states, ". . . [A]ll my thinking is visual. When I think about abstract concepts such as getting along with people, I use visual images such as the sliding glass door. Relationships must be approached carefully otherwise the sliding door could be shattered" (Grandin, 1992, p. 116). Grandin is a professor in animal husbandry and has built an international consulting business designing livestock processing plants. She notes that "visual thinking is an asset for an equipment designer. I am able to 'see' how all the parts of a project will fit together and see potential problems . . ." (p. 116). " . . . I am able

to visualize a motion picture of the finished facility in my imagination . . ." (p. 117).

Another young woman with autism has made an insightful link between "taking things literally" and her use of visualization to think about and organize information:

> Visualization is very helpful for me. Because I visualize, I often take things literally. Someone once asked me, "Where are you?" and I said, "Massachusetts." She said, "What do you want most out of life?" and I said, "a hamburger." It would have been much better for me if she had said, "Where are you in regard to your personal development in life and the universe?" When you get a literal answer, it may be due to the sentence being misinterpreted or the sentence not being long enough. It makes a difference in how a question is answered if a single adverb or adjective is left out. . . . (Lissner, 1992, p. 306)

These persons with autism are suggesting that they think in pictures and visual images rather than in words that are laden with socially based symbolic meanings. Thus, if Ms. Lissner is translating the words spoken to her into her visual images for those words, then she is likely to interpret the meaning and intention of the speaker's question differently.

Janzen suggests that persons with autism have difficulty "organizing information for themselves but if it is organized visually to higlight the meaning, relationships, and sequences, they learn remarkably fast" (Janzen, 1993).

Summary of the Cognitive Realm. Higher functioning persons with autism have a particular cognitive style that is reflected in their cognitive abilities and challenges. We will examine these in more detail in Chapters 3 and 4 when we explore ways to provide instructional and organizational assistance.

The Social Realm

The social realm includes language, communication, and social interaction. At the present time, the communicative and social aspects of autism are its most salient characteristics. For persons with autism, communication and social interaction are often the most challenging aspects of living with autism (Grandin, 1992; Sinclair, 1992; Williams, 1992, 1994).

Social interaction is extremely complex and multifaceted. It involves language, physical, and cognitive components. One must understand the meaning of spoken language within the context in which it occurs. One must be able to perceive the nonverbal social cues of others and be able to control and respond with one's own multiple nonverbal behaviors. And lastly, one must be able to interpret these verbal and nonverbal behaviors in an ongoing social context (see Figure 1.5).

At all of these levels, research and personal accounts suggest that persons with autism face challenges. Coordinating these complex components of social interaction comes naturally to most persons without autism. In contrast, some persons with autism see themselves as lacking these "basic instincts which make communication a natural process" (Cesaroni & Garber, 1991, p. 311). As Temple Grandin states, ". . . I had to learn social interaction skills by using my intellect . . ." (Grandin, 1992, p. 7).

Language Use in Communication. Higher functioning persons with autism often learn to read at an early age and develop excellent vocabularies. At times, however, they may use this language at a higher level than they fully understand. They may have difficulty understanding the meaning of words or concepts they have not directly experienced (Janzen, 1986b).

For example, persons with autism can be confused when the meaning of a word depends on the context in which it is used. Thus, the use of pronouns (he, she), time and space concepts (later, after), and homonyms, or words that sound the same (blue-blew, their-there), can be misunderstood. This has been characterized as using language literally (as described by Kathy Lissner above). Expressions such as "save your breath," "jump the gun," and "second thoughts" may be confusing (Moreno, 1991).

FIGURE 1.5. The Social Realm. In the social realm, persons with autism may have difficulty recognizing verbal and nonverbal social cues and rules.

Persons with autism have reported difficulty understanding words such as *feel* and *know* (Sinclair, 1992). Donna Williams says that "the words 'know' and 'feel' were like 'it' and 'of' and 'by'—you couldn't see them or touch them, so the meaning wasn't significant. People cannot show you a 'know' and you cannot see what 'feel' looks like . . . " (Williams, 1994, p. 68).

A higher functioning person with autism may also be confused by humor and sarcasm—aspects of language laden with hidden social meanings. Dewey (1980) described a young man who became aware that he did not understand the jokes in humorous cartoons. Wishing to correct this, he studied cartoons and discussed their meaning with his parents for several years until he could explain "the point of almost any cartoon" (Dewey, 1980, p. 1). He made this great effort so that he could do what came so easily to others (Dewey, 1980).

Persons with autism sometimes develop very specific interests, study them extensively, and then choose a narrow focus and very few topics in their conversations. In everyday discourse, higher functioning persons with autism may not be aware of or have difficulty monitoring other people's level of interest in what they are saying (Williams, 1994). The reasons for these intense interests may not be clear to the persons themselves (Lissner, 1992). This ability to pursue one's interests, however, is a potential strength and can be directed into significant life pursuits and employment (Grandin, 1992). For

example, Temple Grandin (1992) said that a high school teacher helped her develop her interest in cattle chutes into her international consulting business designing livestock processing plants.

Donna Williams describes herself as "meaning-deaf"; she hears the sounds but not the meaning of the sounds (Williams, 1994, p. 50). Donna states that she had a huge vocabulary and could memorize and mimic entire conversations. But only after years of effort did she begin to "hear with meaning" at least the key words spoken during a conversation. She says:

> As a result I am learning to feel like a part of things . . . and can really understand why people communicate; but although my ability to speak is great, my ability to converse is still not good. . . . I think these communication things are the things that were missing, that I've been trying to find. . . . (Williams, 1994, p. 100)

In order to have a reciprocal conversation, the speakers construct shared meaning by referring to information that is common to both. Communication fails when this process breaks down (Fine, Bartolucci, Szatmari, & Ginsberg, 1994). Linguistic analysis of the speech of nonautistic persons, higher functioning persons with autism, and persons with Asperger's syndrome reveals that all three groups share information equally often when conversing. However, the higher functioning person with autism refers more often to the physical world and less often to previous comments in the conversation. The communication strategies used by persons with Asperger's syndrome are essentially the same as those of persons without autism. Individuals with Asperger's syndrome, however, may more frequently refer to other things that are unclear within the context of the immediate conversation (Fine et al.,1994).

These examples illustrate some of the challenges persons with autism and with Asperger's syndrome encounter with the semantic (meaning) and the pragmatic (social) features of language.

The Ability To Control the Subtle Behaviors of Social Interaction. Another aspect of social interaction is the complex nonverbal interchanges that occur between people. These nonverbal social behaviors require physical movements. We use complex, subtle, and highly coordinated facial expressions, gestures, and vocal intonations when we interact.

As early as infancy, differences in such nonverbal social behaviors are observed in persons with autism. At one year of age, infants with autism may not look at others, show objects to others, gaze back and forth between a desired object and a person (known as joint attention), or orient toward the sound of their name being called as often as infants without autism (Osterling & Dawson, 1994). Toddlers with autism gaze at their mothers and smile at their mothers as often and for the same length of time as children without autism (Dawson & Galpert, 1990). However, they are less likely to coordinate their smiles with eye contact in a single act that conveys communicative intent. In addition, they smile *in response to* their mothers' smile less often (Dawson & Galpert, 1990).

Different infants with autism have highly individual, unique, vocalizations (Ricks, 1975). The facial expressions of children with autism are more often composed of unusual blends of emotions (Kasari, Sigman, Mundy, & Yirmiya, 1990). Children with autism display as many attention-getting and goal-requesting gestures, but fewer of the gestures one associates with expressing social affect than developmentally delayed children (Attwood, Frith, & Hermelin, 1988).

These differences continue into adulthood for some persons with autism. Studies of older persons with autism suggest that some individuals "may not be able to control their own vocal intonation and facial expression to convey the emotions they feel, leading others to misperceive him or her as unfeeling or aloof . . . " (Rumsey, 1992, p. 42).

The social interchanges between people are like a dance; they occur at a certain pace, and

the timing of each person's actions is important. Studies indicate that persons with autism have difficulty with this interpersonal coordination (Attwood, Frith, & Hermelin, 1988; Kasari, Sigman, Mundy, & Yirmiya, 1990). Newson (1980) suggests that some persons with autism have difficulty with "the way people's actions fit in or 'mesh' with each other, both within one person and between people." She notes that this "timing is absolutely essential to our *use* of messages, to create a conversational flow . . . "(p. 1).

Williams (1994) says that the pace of social interactions can make it difficult for persons with autism to catch everything that happens. As noted in the review of the sensory realm, persons with autism may need more time to shift between auditory and visual cues. Grandin (1992) suspects that as a result, persons with autism can have difficulty following the interchanges in a social interaction.

Lawrie Horner provides a picture of what she experiences in social situations and what strategies she uses to make them more optimal for her:

> . . . I find the most difficult social situations are those where I have different relationships with different people, where some people know each other and others don't, where there is no formal activity and so I have to respond as best I can to the utterly confusing social cues, where there is some sense of occasion and everyone is in a sense acting up to that occasion. A perfect example is a cocktail party. I can say for a fact that I get more, socially, from a visit to the dentist than from organized social events. . . .
>
> . . . I've learnt a couple of things about social events. One is not to try and do more than I really can. This means that I hang around in the background and chat briefly with one or two people as they go past, and I don't bother trying to be part of a group. I try to ignore the bizarre impressions that people give me socially—the facial and vocal contortions, the sudden moves of eye, gesture, and head which they do so easily and which strike me as so sudden and confusing. I try not to get fixated on people's hands, waving so distractingly and strangely. I find the hardest thing is to avoid getting paranoid. I always get the impression that everyone is watching me fumbling away in the background and that everyone is talking about me. They may be, of course. (Horner, 1993, p. 22)

Social Perception. Social perception includes the ability to perceive emotional expressions and other social cues. We recognize and react to human socio-emotional cues very early in life. For example, by seven months of age, babies notice when facial expressions and vocal expressions match or don't match (Hobson, 1992).

Studies have found that some persons with autism have difficulty reading vocal or facial expressions. Some higher functioning adults with autism are less able to name the emotions in speech samples, identify the affect in photos of faces, as well as match these with contexts that might elicit each emotion (Macdonald et al. 1989). They also have greater difficulty than persons without autism in matching descriptive words with pictures that show a part of a face expressing the same emotional content (Hobson & Lee, 1989). In some cases they are less able to perceive age and sex-related characteristics of persons in pictures (Hobson, 1987).

These research findings highlight some differences in persons with autism but do not explain these differences. Indeed, persons with autism may go about discriminating different facial expressions in their own way, using their own abilities. For example, young adults with autism are better than young adults without autism at identifying emotions in pictures of whole faces that are upside down! (Hobson & Lee, 1989). Further research of visual perception may clarify why some higher functioning persons have difficulty discriminating facial, gestural, and vocal emotional expressions and recognizing how different expressions are coordinated with each other (Hobson, 1992).

Wing (1992) reports that one young man with autism said with great sadness: "People give each other messages with their eyes but I don't know what they are saying . . ." (p. 131).

Social Cognition. Perhaps the most mysterious aspect of our ability to interact with others is how we know what to do in social situations, infer the intentions of others, empathize with others, interpret social cues, and see another person's point of view. These are all aspects of social cognition.

Persons with autism and their parents and teachers have noted that understanding and learning from social events is a particular challenge. Social situations are full of subtle cues, unspoken rules, and meanings derived from the social context. Although social situations are very complex, most persons without autism seem to have an ability to interpret and "know what to do" in social situations with ease.

One young woman with autism explains:

> It is very difficult for even a higher functioning autistic adult to know exactly when to say something, when to ask for help, or when to remain quiet. To such a person, life is a game in which the rules are constantly changing without rhyme or reason. (Carpenter, 1992, p. 291)

Studies have found that some children with autism seem to have difficulty identifying what other people know in a situation. This has been studied in various experimental situations (Baron-Cohen, 1989; Frith, 1989). For example, children with autism watch as an object is taken from a box and hidden in a closet. Later, a person who has not seen this occur enters the room. When the children with autism are asked "Where will this person look for the object?" some children say "the closet." Thus the children answer as if they think the other person knows the same things that they do. This result has been interpreted to mean that some, but not all, children with autism have difficulty knowing the mental states of others (Baron-Cohen, 1989).

An alternative possibility is that persons with autism focus on a portion rather than the overall situation or context (Happe, 1994). In another study, adults were presented with stories about everyday situations where people say things they do not mean literally. Compared to persons without autism, some of the adults with autism had difficulty predicting what people in the story would say or explaining why they would say those things (Happe, 1994). Upon close analysis, it appears that these adults gave answers that fit with a portion of the story but did not fit the overall social context in the story. This is consistent with Frith's (1989) theory that some persons with autism have difficulty using the most coherent, overall information available in a situation.

Developmental theorists argue that social cognition (such as the perspective taking just described) begins with the infant's and toddler's desire and ability to imitate others, engage others in interaction, and use symbolic play. "The child with autism engages in less spontaneous imitation of others. This may interfere with the development of reciprocity, joint attention, and awareness of emotional and mental states in self and others" (Klinger & Dawson, 1992, p. 383). By nine months of age, infants point things out to their mothers and look back and forth between the object and their mothers' eyes (Klinger & Dawson, 1992). It seems that the infants are trying to get mom to think about the same thing they are thinking about. This is called having "joint attention." In some cases, young children with autism are less likely to try to get others to engage in joint attention with them (Klinger & Dawson, 1992). Some children with autism engage in little symbolic play, and others develop symbolic play later than children without autism (Jarrold, Boucher, & Smith, 1993).

Dawson and her colleagues have proposed a possible reason children with autism do not engage in these early social behaviors (Klinger & Dawson, 1992). Humans are born with complex and sensitive sensory systems through which they take in all types of environmental stimulation. To control this potential bombardment, humans also have innate neurological systems that regulate their level of arousal and help them orient toward and detect novel stimuli. Research suggests that these neurological systems may not work as well in children with autism. Thus, they may be too easily overaroused and have a very narrow range of optimal stimulation within which they are able to attend to stimuli. Perhaps when stimulation is

too great, the child with autism withdraws and stops attending (Klinger & Dawson, 1992).

Many children with autism actively explore and learn about physical objects upon which they can repeat the same actions. It may be that because mechanical events with objects are predictable and in the child's control, these events can be more easily assimilated and are less likely to elicit overarousal and inattention (Klinger & Dawson, 1992). In contrast, "social, emotional, and linguistic stimuli are, by nature, relatively unpredictable and indeterminate" (Klinger & Dawson, 1992, p. 165). This may be the reason that the child with autism has difficulty processing social information, such as vocalizations, gestures, and facial expressions. "Without the ability to impose meaning upon the ever-changing flow of social information, the person with autism may be overwhelmed and overaroused by such information, and respond by failing to attend or even withdrawing from such stimuli" (Klinger & Dawson, 1992, pp. 165–166).

Summary of the Social Realm. Persons with autism face challenges in many aspects of social functioning. Some individuals have difficulty with the semantics of language and with conversational flow. The multiple nonverbal behaviors involved in social interaction can be hard to perceive and to coordinate. Persons with autism may also have difficulty inferring what other people are thinking or feeling. At the present time it is not clear why these challenges occur. They may begin in infancy and be related to sensory perception and cognitive style. Chapter 4 provides methods for helping young adults with autism to gain social knowledge.

UNDERSTANDING THE PERSPECTIVE OF PERSONS WITH AUTISM

The social realm just described is a two-way street. One of the most important messages in this guide is that *when one strives to teach and befriend a person with autism one must set aside the notion that one knows why people do what they do.*

As social beings, humans observe and interpret the actions of others based on their own previous stockpile of social and personal experiences. People tend to feel certain emotions automatically when others do or say certain things. This is an important part of being a socially adept and sensitive person.

Thus people constantly make judgments in social relationships. Most people think that they know other persons' intentions when they do or say something. For example, if a person acts aloof and won't look at us, then we assume he or she doesn't want to talk to us or doesn't like us. If a person talks constantly and never lets us get a word in edgewise, then we assume the other person wants to dominate the conversation or be the center of attention. In typical social experience, this is often what these actions mean. But with persons with autism, this is often the wrong interpretation.

Donna Williams describes what she learned from her psychologist/teacher about the differences between herself and others:

> He tried to explain gently to me that other people generally didn't have these difficulties, and that was why they hadn't understood. He explained how other people got all the bits working at once. How they managed to get the mechanics of so many things going at the same time was nothing short of a miracle. . . . No wonder, in the face of my apparent intelligence, they were surprised and angered that they weren't making any sense to me and so assumed I wasn't listening or didn't want to. No wonder they were confused and hurt as to why I could talk so well and yet not converse "with" and so assumed I was merely selfish or arrogant as I continued rigidly on my own topics. No wonder they didn't know how I felt if I couldn't get emotional expression and words going at the same time and figured I didn't care or had no feelings. . . . (Williams, 1994, p. 86)

CHAPTER SUMMARY

Higher functioning persons with autism process information differently. This difference is neurologically based and evident at a very young age. A wide array of research findings, parent and teacher observations, and personal experiences of persons with autism have been described in this chapter. These were organized into three realms—sensory, cognitive, and social experiences—although it is clear that these overlap in complex ways.

It is important to remember that each individual with autism is unique and may or may not experience all of the sensory, cognitive, and social challenges described here. Higher functioning persons with autism have average to above-average mental abilities but vary widely in the severity and number of challenges they face due to autism. In terms of everyday functioning, some persons need little or no assistance, whereas others need daily assistance in various forms.

Recent discoveries have greatly increased our understanding of autism. The insights provided by higher functioning persons with autism are especially significant. With this new information, persons with and without autism are now better able to understand each other.

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