Working with Autism and Other Social-Communication Disorders.

Since the introduction of supported employment, and the implementation of legislation such as the Rehabilitation Act Amendments of 1986 and the Developmental Disability Assistance and Bill of Rights Act (1984), rehabilitation counselors have been increasingly responsible for serving a diverse pool of clients. The mandate to support individuals with the most significant disabilities is further strengthened in the 1998 amendments to the Rehabilitation Act. The language of legislation and policy reflect high expectations for the vocational success of such individuals, many of whom were previously deemed unemployable.

Graduate programs in Rehabilitation Counseling tend to stress psychosocial adjustment to disabilities, counseling methods, and functional limitations. Problems associated specifically with developmental disabilities such as communication disorders, behavior issues, and adaptive deficits receive less attention in curricula (Bolton & Cook, 1997). As a consequence, counselors may be inadequately prepared to serve individuals with the most severe disabilities in community contexts. The aim of this article is to provide rehabilitation professionals with (1) detailed definitions and descriptions of autism (2) a theoretical overview of the literature on autism and related disabilities. (3) effective approaches and strategies based on primary sources, and (4) specific recommendations. The purpose of the article is to help the rehabilitation counselor maximize the success of individuals with autism and related disabilities. The paper is organized in three sections. First, definitions of autism including various models and theories of autism are provided. Next, an analysis of first-hand accounts provides insights into how individuals with autism experience the world. The article concludes with a series of recommendations to improve rehabilitation counselor interactions with individuals who have autism and other social-communication disorders.

The Nature of Autism

Autism is one of a family of developmental disorders that influences social, communication, and vocational abilities. Specific labels included under the broader heading of Pervasive Developmental Disorders including Asperger’s syndrome, autism, Rett’s disorder, and Childhood Disintegrative Disorder (American Psychiatric Association, 1994). Other neurological disabilities, including left hemisphere traumatic brain injury, severe learning disability, language disorders, attention deficit disorder, and Tourette’s syndrome, share many features with autism (Frith, 1991, Tsai, 1992; Yeung-Courchesne & Courchesne, 1997). People who have autism and related disabilities sometimes experience secondary problems such as obsessive-compulsive disorder, language difficulties, and attention deficit disorder (Frith, 1991, Tsai, 1992). Many individuals with milder forms of autism are first diagnosed as learning disabled or emotionally disturbed (Tsai, 1992). Although not precisely accurate, ‘autism’ is used as an umbrella term meaning ‘severe social-communication disorder of developmental origin’ throughout this article.

Autism Defined

Autism is a relatively low-incidence developmental disability that, according to Frith (1991), results in impairments of socialization, communication, and imagination. In an article describing her experiences, Donna Williams (1994a), a person with autism, defined the disability as a pervasive developmental disability affecting recognition and comprehension including proprioception, kinesthetic sense, sense of self and other, visualization, sequencing, synthesis, analysis, and retrieval. People with autism often exhibit significant language problems such as delayed or absent speech, perseveration, and echolalia. Solitary, repetitious, patterned behaviors are often favored from infancy, sometimes to the exclusion of explorative and social behaviors (Wing, 1991). The majority of people with autism are thought to have severe intellectual disabilities (Yeung-Courchesne & Courchesne, 1997). Most people who are so labeled require supervision, support, and assistance throughout their lives.

The nature and severity of autism has profound implications for the potential success of the individual in the workplace. Responses and behaviors of people with autism can be mystifying. For example, strong emotional reactions to touch, sound, or unannounced changes may appear disproportionate to the problem. Patterned or ritualized behaviors may seem odd, and speech may be monotonic, formal, or unusual in content or delivery. Although there are no simple answers as to why individuals respond and interact as they do, various models have been proposed.

Historical and Theoretical Models

Our understanding of autism has evolved significantly over the past 50 years. In the early 1940s Leo Kanner and Hans Asperger independently used the term “autistic” to describe children who appeared to have unusual reactions to sensory stimuli, exhibit stereotyped and repetitive behavior, lack initiatory responses, desire sameness, and develop strong attachments to objects rather than people (Wing, 1991). Although both Kanner and Asperger believed autism to be an inborn biological disorder, Bruno Bettelheim reinterpreted autism as a psychiatric disability resulting from parent-child pathology (Yeung-Courchesne & Courchesne, 1997). Neuropsychological research has confirmed Kanner’s theory that the cause of autism is primarily biological, and that differences in perception and behavior can be attributed to neurological differences (Frith, 1991; Yeung-Courchesne & Courchesne, 1997).

Unfortunately, Bettelheim’s ideas seem to have persisted in the minds of many professionals and lay persons, causing parents of children with autism to feel inadequate or stigmatized (Wing, 1991).
Neurobiological Model

Recent theories of autism have evolved from clinical observation and biological studies. Researchers agree that problems associated with autism, such as the inability to plan, shift attention, or respond to novel situations result from impaired structure and function of the brain. Different theories attribute autistic perception and behavior to a variety of root causes such as: problems adjusting spatial attention; difficulties modulating arousal and attention; stimulus selectivity; inability to engage in joint attention; faulty executive function; and poor working memory (Yeung-Courchesne & Courchesne, 1997). Researchers suggest that difficulties with communication, social interaction, organization, and attention are symptomatic of damage to specific areas of the central nervous system. However they disagree on the exact site of the damage (Cox & Mesibov, 1995; Hughes, Russell & Robbins, 1994; Shea & Mesibov, 1985).

Clinical-Behavioral Model

Although researchers who examine autism from clinical and behavioral perspectives do not reject neurobiological theories, they interpret autism differently. For example, Duchan and Palermo (1982) conceptualized autism as a thematicization disorder. Thematization is the cognitive ability to think representationally; thematization gives meaning to images, movement and speech. When this ability is impaired, the individual has a difficult time understanding events, sequencing, or perceiving order.

Duchan and Palermo (1982) speculated that individuals with autism create meaning in ways that differ from those without autism. For example, rhythmic, self-stimulatory behaviors may have a temporal regulatory function, literally helping people keep time. Likewise, perseveration could indicate difficulty changing themes. Unusual use of language such as pronoun reversal and metaphorical speech (e.g., referring to five crayon colors by the names of the Dion quintuplets (see Wing, 1991)) could indicate atypical patterns of thought. Within this frame, contextually inappropriate speech and actions, as well as repeated words and movements, are explained as problems in creating and terminating “themes” (Duchan & Palermo, 1982).

Proponents of theory of mind posit that people with autism lack the ability to comprehend thoughts and experiences that occur outside of themselves (Baltaxe & Simmons, 1992; Happe, 1991; Russell & Jarrold, 1998). Difficulties understanding what is salient to another person can result in communication that appears irrelevant or bizarre to a communication partner (Duchan & Palermo, 1982). Further, problems recognizing the mental states of other people appear to interfere with the ability to identify with others or to understand another person’s point of view. These problems may prevent the development of a concept of agency (Hughes, Russell & Robbins, 1994). In other words, a person with autism might have a difficult time determining who is responsible for a given action.

Dyspraxia Model

The introduction of facilitated communication (FC) in the early 1990s prompted a re-examination of autism. FC, a method whereby individuals with significant communication disorders are physically supported by a facilitator to type or point to letters, numbers, or symbols, yielded circumscribed evidence that people with autism and other severe developmental disabilities might be able to communicate at a more sophisticated level than previously thought (Biklen, 1990; Biklen & Cardinal, 1997). Although the claims of authentic communication through FC have been strongly contested (Green & Shane, 1994), renewed interest in this population has resulted in a fresh examination of autism.

Venter, Lord and Schopler (1992) noted that professionals tend to equate the inability of people with autism to respond in predictable ways with deficits in comprehension. Biklen (1993) and Donnellan, Sabin & Majure (1992) reconceptualized autism as a disorder of praxis (i.e., voluntary movement) rather than thought. In brief, dyspraxia theory explains problems associated with autism as difficulties in carrying out one’s intentions. The dyspraxia model of autism provides an explanation for the acute frustration and disparate performance seen in people with autism (Barron & Barron, 1992, Park, 1982).

Social Model

More than other developmental disabilities, autism has been medicalized. Life with autism begins with a diagnosis that has a poor prognosis for recovery. The behaviors of individuals with the label are called symptoms. These powerful concepts propel helping systems that, in turn, crank out favored treatments of the day. Thus, autism is reified as a disease. Yet it is possible to conceptualize autism as difference rather than as dysfunction. Jim Sinclair (1992), a person with autism, compared interactions between individuals with and without autism to a cross-cultural interaction. Although autism does not meet the strict definition of culture (e.g., it is not generally passed from one generation to the next), sensory, experiential, and cognitive differences may provide a “design for living” much as sensory and experiential differences define Deaf culture (Shapiro, 1994).

Each of the models described above contributes to our understanding of autism. Yet, as Courchesne, Townsend and Chase (1995) point out, it is important not to look at the end products of autism for development of an overarching theory in the same way that it makes no sense to look at cold symptoms to understand the cause and nature of colds. Further, researchers agree that any one perspective cannot alone describe the challenges faced by people with autism (Yeung-Courchesne & Courchesne, 1997; Shea & Mesibov, 1983).

The Autism Experience

Although theories of autism are useful, none accurately describes the lived experience of autism. Autobiographies and first hand accounts by and about individuals with autism provide a unique window into their experiences.

Method

The initial phase of a larger study, the research presented here was conducted to establish an “insider’s” perspective of the experience of autism and related disabilities. First-hand and
autobiographical accounts by 13 authors, comprising approximately 1700 pages were examined. Five of the authors were individuals with autism; four were parents of children and adults with autism. One autobiography was written by a mother and her autistic son. The remaining three texts include an analysis of the autobiographical writing of three adults with Asperger Syndrome, an interview, and a book review.

Initially, three autobiographies (Grandin, 1995; Park, 1982; Williams, 1994b) were carefully read and key themes were identified. Themes were continuously compared to phenomena described in the remaining texts in order to identify commonalities as well as disagreements. All of the autobiographers discussed the difficulties and experiences with sensation, attention, affect, communication, and social interaction. Many individuals with autism and all parents suggested strategies for coping with these difficulties.

Findings

People labeled autistic describe an unusual relationship with the world around them. From an early age, autobiographers distinguished the "real world" from how they personally experienced the world (Barron & Barron, 1992; Grandin, 1995; Sellin, 1995; Williams, 1992). Donna Williams (1992) characterized her relationship to others as mutually incomprehensible. Just as family members could not interpret the meeting of her solitary play, she could not understand their words or actions.

Sensation. Differences in neurological development can result in altered sensitivity to sound, touch, visual input, and movement. Sensation may be fragmented, altered, variable, increased, or decreased. For example, Sean Barron described his early memories of people as fragmented: "Even when I saw them they were still in pieces" (Barron & Barron, 1992, p. 21). Autobiographers reported a limited capacity to both filter stimuli and to experience more than one sensation at any given time (Grandin & Scariano, 1986; Williams, 1994b).

Sensitivities to touch, sight and sound can result in a widely reported experience of what Williams (1992) has termed "shut down." In his autobiographical book of poetry, Birger Sellin (1995) described "shut down" as an acute panic attack that is brought about by sensory and emotional bombardment. The shut down experience appears to be worsened by intrusions that cannot be avoided or are of uncertain duration.

Attention. Donna Williams (1994a) observed that she, as well as others with autism, seemed to have a significant limitation ability to attend to more than one event at a time. This observation is confirmed by Courchesne and his colleagues who noted both a dissociation between auditory and visual attention, and an inability to rapidly shift attention in individuals with autism. They stated that deficient attention contributed to the social and cognitive delays in autism (Courchesne et al., 1994), perhaps due to the forfeiture of attention to one sensory mode for another (e.g., touch over vision). Although attentional limitations interfere with learning, the ability to focus acutely on one skill or activity to the exclusion of other stimuli can also lead to proficieny. Individuals with autism often have strong interests and some develop extraordinary talents. Examples were numerous in the autobiographical literature: Jesse Park (Park, 1992) became a respected artist; Temple Grandin (1995) gained international recognition as a designer of livestock equipment; and Donna Williams (1992) taught herself to play piano, developing her own notation system. Others exhibited skill in poetry, music, and mathematics (Akerley, 1992; Sellin, 1995; Sullivan, 1992).

Emotion. Distress and anxiety are common emotional states for people who have a difficult time interpreting events and filtering stimuli. Parents of people with autism have noted that their children experience tremendous distress over seemingly minor problems such as an unexpected event or minor error (Park, 1992; Sullivan, 1992).

Certainly, not all emotions experienced by people with autism are negative. Donna Williams described the intense pleasure she received from reflected light patterns, stable fluctuations of sound, jumping, playing music, or watching a fire (Blakely, 1992, Williams, 1994a; Williams, 1994b). Likewise, Temple Grandin reported experiencing acute pleasure when interacting with animals or while involved in complex perceptual-spatial tasks (Grandin & Scariano, 1986; Grandin, 1995).

Communication. Even for individuals with autism who are very capable, problems with communication are often quite fundamental. Individuals with autism may misinterpret situational nuances, fail to consider context, and have difficulty distinguishing the essential from the trivial (Dewey, 1991; Happe, 1991). Temple Grandin (1992) wrote that, as a child, verbal communication was extremely difficult. She screamed when she could find no other way to communicate. Donna Williams (1994b) reported that she was often able to understand words, sentences, even contexts, without grasping the significance of a spoken message. Difficulty initiating conversations, use of idiosyncratic language, failure to listen to or follow through on requests, and specific problems with receptive and/or expressive communication are commonly reported in literature on autism and related disabilities (Cox & Mesibov, 1995; Frith, 1991; Townsend & Courchesne, 1994).

Although several authors reported that they did not feel loneliness, sexual desire, or need for friendship in the same way that nonautistic individuals do, they sometimes desired relationships and friendship (Blakely, 1992; Grandin, 1995; Sinclair, 1992). Making friends is complicated by social deficits. The subtleties of body language, facial expressions, tone of voice, and physical proximity can be difficult for people with autism to interpret or produce (Grandin, 1995). Even the intentions and motivations of others are often difficult to comprehend (Sellin, 1995; Sinclair, 1992).

Effective Strategies and Approaches

Venter, Lord and Schopler (1992) noted that capable individuals with autism were more likely to develop good coping strategies than others. Nonetheless, even the most significantly disabled individuals can acquire useful strategies when approached consistently and respectfully. Below, the coping strategies reported by individuals with autism are delineated. Effective approaches to supporting and assisting people with autism, gleaned from first-hand accounts by parents and individuals with autism, are also provided.
Compulsions also appear to be common among people with autism. This may be due to the fact that people with autism do not experience time and place in exactly the same way that people without autism do. Courchesne, Townsend, Akshoomoff and their colleagues (1994) asserted that interactions often lack context or temporal continuity for individuals with autism. Temple Grandin (1995) and Birger Sellin (1995) described a driving need to keep to a schedule. Knowing what to expect kept them calm. Donna Williams (1992) found color or pattern soothing. Changes of plans, transitions between activities, waiting, and other time-related events can cause extreme anxiety in an individual for whom passage of time seems discontinuous. Birger Sellin (1995) used time markers such as meals, rising, and retiring to help control his anxiety.

Sensory Manipulation. Autobiographers used a wide range of strategies to deal with sensory overload. Donna Williams controlled visual overload by using peripheral vision to view a stimulating object (Blakely, 1992). Temple Grandin (1995) wore tinted glasses to reduce visual stimulation. She also used what she called a squeeze machine. The squeeze machine, designed by Grandin, provided firm, controlled pressure to the entire body, resulting in a sense of calmness and reintegration (Grandin & Scariano, 1986).

Both Temple Grandin (1995) and Donna Williams (Blakely, 1992) reported using their sense of touch to better understand things. Because her visual sense was unreliable, Williams used touch to establish a boundary between herself and objects. She did this by pouting, slapping, or tracing. Grandin found touch to be helpful in establishing her sense of physical location, but noted that touch could also be troublesome due to her tactile defensiveness.

Recommendations for the Rehabilitation Professional

When interacting with an individual with autism, it is important that the rehabilitation counselor understand the person first as a unique individual. However, specific approaches and strategies that other people with autism have found helpful can be quite useful. Following are five specific recommendations that may be valuable to rehabilitation counselors as they plan for and with individuals who have autism.

Work with, rather than against, interests and abilities. Many individuals with autism have unique strengths and strong interests. Accommodating an individual's interests and abilities in creative ways produces better outcomes than trying to fit the individual to certain jobs or environments. For example, a person with autism might excel at tasks involved in stock work such as ordering and organizing items. If the job also requires waiting on customers, the individual may have difficulties. A person with an unusual memory may be very well suited for employment that requires command of many discrete pieces of information. Such abilities are in demand in settings as diverse as business offices, bookstores, and warehouses. An individual with artistic or musical abilities might enjoy working for a theater or school of music. Someone with a fixation on a specific topic such as horses might find satisfaction working for a riding stable.

Introduce changes gradually and thoughtfully. When assisting individuals with autism toward their vocational goals, it is important to choose ones battles wisely. First, the counselor must take time to assure that the person with autism shares his or her understanding of problems and goals before changes are made. Second, changes should be considered carefully. Dewey (1991) remarks that small victories gained through great effort may not be worth the struggle. Even with successful learning, generalization of knowledge to new settings can be difficult (Frith, 1991). Third, the counselor needs to understand the function of various behaviors. Some changes may not be beneficial to the person. For example, rocking, finger flicking and humming may have important self-regulatory functions. Such behaviors should be accommodated rather than extinguished (Williams, 1994a).

Communicate clearly and directly. The effectiveness of the counselor's interventions depends as much on approach as on content. People with autism may not understand indirect communication such as figures of speech, body language, tone of voice, and facial expressions. They tend to take words literally. This could be due less to naivete than to unique perceptions and language processes. In order to avoid misunderstandings, one should be clear and specific, avoiding euphemisms and figures of speech. Not only do people with autism have a difficult time interpreting nonverbal messages, they may also send faulty social cues. For instance, during a job interview, lack of appropriate eye contact might inaccurately convey a lack of interest to a potential employer.

Interacting with a person with autism through e-mail or notes may result in better understanding than face-to-face conversations. Temple Grandin (1995) states that, for her, reading is easier than listening, and observing easier than reading. Donna Williams (1994a) suggests interacting through shared activities or typing rather than conversation to avoid sensory bombardment.

People with autism may become upset unexpectedly. Strong expectations, anticipation, and the emotional reactions of others can be overwhelming for a person with autism, as can sensory input such as light, sound, touch, and texture (Williams, 1994a). A calm voice and a firm, persistent, and confident manner is helpful in these situations (Torski, 1992). Minimizing eye contact and using prompts sparingly are also helpful approaches (Happe, 1991; Williams, 1994a).

Provide appropriate feedback. Like others, individuals with autism may be sensitive to criticism. However, they may also feel responsible for information and situations that are beyond their knowledge or control. They may not be able to detect when something is done right, requiring others to tell them (Dewey, 1991). Genuine compliments and feedback are effective. Akerley (1992) suggests that one explicitly distinguish directives from advice, pointing out to the person that it is sometimes necessary to correct their errors as a short cut to success. Gentle encouragement may allow the individual to incorporate new skills and activities in an atmosphere of trust (Williams, 1994a).
Plan for relaxation and physical activity. People with autism appear to experience a great deal of anxiety just performing ordinary activities. Interactions, transitions, unexpected changes, demands, and sensory stimuli can all be extraordinarily stressful for persons with autism. For many, exercise and movement create a sense of calm (Grandin, 1995; Selin, 1995). When possible, physical activity, such as walking, should be scheduled into the workday. Task such as delivering mail, running errands, or unloading a truck can provide relief from stress and anxiety.

Conclusion

Children are generally on their way to mastering the developmental tasks of communicating effectively, controlling impulses, and participating in social groups by the time they enter school. Nonverbal communication, such as "reading" facial expressions and body language, and interpreting emotions seem to come naturally to most children. However, children with developmental disabilities by definition do not develop along the same paths as nondisabled children (Goldberg, 1981). According to Courchesne, Townsend and Chase (1995) pervasive developmental disabilities affect the individual from infancy. Individuals with autism may discover methods of interaction and personal organization that differ radically from those that are easily learned by children who do not have impairments.

Donna Williams (1994a) warns us not to view people with autism as slow or broken versions of nonautistic individuals. The experience of autism must be understood as unique. Some people with autism even object to person-first language. Jim Sinclair (personal communication) states that "person with autism" suggests that the autism can be separated from the person. As he put it, "I am autistic because I cannot be separated from how my brain works." People with autism experience the world differently and should be approached with openness and respect. In order to understand autism, strengths must be considered as well as deficits (Happe', 1991; Yeung-Courchesne & Courchesne, 1997).

Yeung-Courchesne and Courchesne (1997) suggest that professionals not put too much stock in formal assessments of persons with autism. They note that IQ measures are part and parcel with neurological differences: a product of neurobiology, not a cause. As Duchan (1986) remarked, the expression of knowledge may not be equal to what that person actually knows. Therefore, multiple methods for teaching as well as for assessing understanding are advisable.

References


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considered...
High rates of comorbidity between SPCD and other seemingly disparate disorders (including conduct disorder, ADHD and disorders of known genetic origin) raise questions about the utility of this diagnostic category. SPCD is probably best conceptualized as a dimensional symptom profile that may be present across a range of neurodevelopmental disorders, although there is an urgent need to investigate the latent structure of SPCD using consistent diagnostic criteria. In addition, social communication and aspects of pragmatic language may be dissociated, with the latter heavily influenced by Kozyavkin's Method, childhood autism, autism spectrum disorders, rehabilitation.

INTRODUCTION. Today, one of the most urgent medical and psychological problems is the rehabilitation of a very large group of patients—persons with autism spectrum disorders (ASD). Rehabilitation of children with autism carries great social and economic burdens, including the fact that when they become adults, these patients remain ill and have corresponding needs. According to different data, lifetime care for one patient with autism costs $3.2 million US, so for the whole contingent of patients the figure will reach $137,000,000,000 US [1].