Stress and Coping in Autism

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In the public perception, the word autism conjures up an image of a person rocking back and forth, hands flapping in front of eyes that seem to focus in an unknown space—a person remote from and disinterested in the social milieu (Cowley, 2000, 2003; Nash, 2002). For many years, professional descriptions, definitions, and common assumptions about people with autism have reinforced that image and named the unusual ways of moving and acting as "behaviors." Within the professional world that arranges and provides support for people with autism, the word "behavior" often became shorthand for bizarre, bad, repetitive, self-stimulatory, or useless ways of spending time. Much of the literature is concerned with manipulating, managing, or eliminating behaviors with little or no reference to how these might reflect the experience of the labeled individual. Moreover, the professional models for addressing autism are usually couched in social definitions (e.g., avoiding eye contact, disinterest in social interaction, no imaginative play) that reflect our experience as much as, or more than, that of the labeled person. Because of the communication difficulties pathognomonic to the disorder, these individuals often have difficulty explaining their behavior. Thus, we end up assuming our experience of them matches their own experience, an inadequate substitute for their perspective at best.

Despite this obvious breech, many professionals believe that we already understand what autism is, if not the exact cause of the disorder (Donnellan, 1999). In fact, the description of autism is too often a teleological exercise with the same symptoms used to both describe and explain it. When one asks why the
person displays "autistic symptoms," one is told that he does it because he "has autism," or because he does not have a "theory of mind module," which is why he is autistic, and his autism is why he does what he does.

If parents and professionals are to begin to understand the phenomenon called autism, and through this understanding provide personalized support, it seems evident that the expressed experience of those who are categorized as autistic must be included (Lovett, 1996). Therefore, in this chapter, the words of those with autism will be used to explore the stress with which these individuals live. We will use the literature on "movement differences/disturbances" (Donnellan & Leary, 1995; Leary & Hill, 1996) to help guide that exploration and identify accommodations that might help to minimize stress.

Research that explores the relationships between autism and movement differences has been accumulating slowly since Kanner (1943, 1944) first described repetitive movements, insistence on sameness, differences in the use of facial expression, and limited use of gesture as characteristics of autism. Our reviews of literature have uncovered historical references to movement differences for people with symptoms associated with autism (Earl, 1934; Kahlbaum, 1874/1973; Rutter, 1966; Rutter, Greenfield, & Lockyer, 1967), as well as more recent research (Donnellan & Leary, 1995; Leary & Hill, 1996). Young and Donnellan (1997) found that the movement differences most commonly cited in the literature include gross and fine motor difficulties (Gittelman & Birch, 1967); initiation failure or difficulties (Damasio & Maurer, 1978; Maurer & Damasio, 1982; Rutter et al., 1967; Schopler, Reichler, & Renner, 1986; Wetherby & Putting, 1984); awkwardness and clumsiness in arms and legs; facial-grimacing or teeth-grinding (Bender, 1947; Kanner, 1943); and hyperkinesis or hypokinesis (Gittelman & Birch, 1967; Menolascino, 1965; Rutter, 1966; Rutter, et al 1967; Wortis, 1958). Although movement differences are frequently mentioned in the literature on autism, few papers exist that focus on the implications these symptoms might have for the people labeled with autism. Early works by Damasio and Maurer (1978) and Maurer and Damasio (1982) are particularly noteworthy exceptions.

Our work over the past 12 years has focused on understanding symptoms of movement differences in people labeled with autism and in people with other labels, such as Parkinson's disease, postencephalitic Parkinson's disease, Tourette's disorder, and catatonia (Donnellan & Leary, 1995; Leary, & Hill, 1996; Leary, Hill, & Donnellan, 1999; Patterson 2002a, 2002b; Strandt-Connroy, 1999; Strandt-Conroy & Donnellan, in preparation). Our emphasis has been on understanding the symptoms commonly associated with movement differences, rather than on the syndromes, diagnostic categories, or etiologies. Our interest has centered on the possible effects that differences in movement may have on a person's ability to organize and regulate movement in order to communicate, relate to others, and participate in his or her family and community. Conversely, we have an interest in how moving differently affects the image a person projects to others, leading others to make assumptions about a person's interests, potential for forming relationships, intellectual functioning, and emotions.

Through most of this chapter, we use the term "movement difference," rather than "movement disorder" or "movement disturbance," to acknowledge that not all of the differences that people experience need be viewed as pathological. Rather, moving and behaving differently is merely part of their day-to-day experience. For example, the person who twirls in a small circle after standing or before sitting may be described as moving differently. The act of twirling does not impact negatively on life and, for most people, is not necessarily a problem. It may, in fact, be an accommodation or a way that a person may temporarily get around difficulties in making the transition from standing and sitting. It may thus be seen as no more odd than straightening one's tie before beginning a speech. When movement differences cause harm or truly disrupt a person's ability to participate, the term "disturbance" may be applied. Difficulties with self-injurious or aggressive behaviors or difficulties of overall activity, such as stupor or frenzy, would fall into the category of movement disturbance. The terms "disorder" and "disturbance" are commonly used in the literature for other diagnostic categories as well. For these reasons, we will generally use the term "movement difference" except where movement disturbance would obviously apply.

This chapter offers information on the symptoms of movement differences reported and observed for some people with autism. We will present the range and intensity of expression of symptoms with first-person accounts of how the symptoms have affected people's lives. We will consider stress both as a trigger for unusual, atypical, or uncontrolled movements, as well as an outcome for people who have significant differences in their ways of moving and behaving. Finally, we address some of the implications for supporting people challenged with these differences.

**What Is a Movement Difference?**

Leary, Hill, and Donnellan (1999) defined a movement difference as a difference, interference, or shift in the efficient, effective use of movement. It is a disruption in the organization and regulation of perception, action, posture, language, speech, thought, emotion, and/or memory. Typically, the word "movement" refers to observable actions, such as posture, muscle tone, head and eye movements, facial expression, vocalization, speech, whole body movements, reaching, gesturing, running, and walking. Our use of the word movement is consistent with research that considers internal mental processes of sensory perceptions (e.g., touch, taste, smell, vision, hearing, proprioception), language, thoughts, and emotions as aspects of human movement.

There is a unity of perception, action, emotion, and thought reflected in the writings of many authors interested in movement. The physicist, martial artist, and movement innovator Moshe Feldenkrais (1972) wrote: "Our self-image
consists of four components that are involved in every action: movement, sensation, feeling and thought” (p. 10). In his fascinating book, *Awakenings*, Oliver Sacks (1990) wrote of the experiences of his patients with postencephalitic Parkinson's disease. The diagnosis for these patients was movement disorder. The variety of manifestations of symptoms encompassed many hidden aspects of human experience, including difficulty with perception of the passing of time, interest in normal activities, fatigue, memory, and recurring thoughts.

Esther Thelen (1995), a developmental psychologist, has researched and described movement in relation to child development. In her view, perceptions, movement, thoughts, and emotions can be linked by having coincidentally (and possibly routinely) co-occurred. Experience may selectively reinforce them as a bundle. They can be unbundled or softly assembled as required by the context. The individual is always operating within an environment or context and, as the context changes, systems scan, adjust, and shift as necessary to meet new demands. These contextual shifts play a vital role in movement. Context changes come together in such a way as to allow the movement to emerge; the movement and, indeed, the person are part of the context.

No one component is causal in determining the movement. As these are dynamic systems, all components and context determine the product (Thelen, 1995; Thelen & Smith, 1994). Thelen and Smith further explained, "even behaviors that look wired in or program-driven can be seen as dynamically emergent: behavior is assembled by the nature of the task, and opportunistically recruits the necessary and available organic components (which themselves have dynamic histories) and environmental support" (p. 73).

An example of this is seen in the dynamic nature of speech. Speech is not lost or gained; rather it emerges when all components and context, appropriately regulated and organized, allow its production. For many persons, autistic or not, stress makes speech difficult and even impossible at times. Paradoxically, for some people with movement differences, stress can help produce speech. The late Arthur Shawlow, Nobel laureate and father of an adult son with autism, reported that his son could say a complete, and original, context-appropriate sentence about once every 8-10 years. He asked an audience at the Autism Society of America conference how many parents had similar experiences and about 15% of parents raised their hands. They met briefly and compared notes. Most of the labeled children of these individuals were able to speak under extreme, often negative, circumstances. Some had only spoken once or twice in a lifetime (A. Shawlow, personal communication, July, 1996).

### INTERPRETING SYMPTOMS OF MOVEMENT DIFFERENCES IN PEOPLE WITH AUTISM

Parents, teachers, and people who themselves experience these movement differences have consistently reported disturbances of sensation and movement associated with autism (e.g., Rubin et al., 2001). Researchers have studied autism in relation to a number of disturbances of sensation and movement. These findings are summarized in table 8.1.

<table>
<thead>
<tr>
<th>Symptoms</th>
<th>Research</th>
</tr>
</thead>
<tbody>
<tr>
<td>Apraxia/dyspraxia or difficulties in motor planning and sequencing of movements</td>
<td>Ayres (1979); Biklen (1990); Brasic, Barnett, Will, Nadrich, Sheitman et al. (2000); DeMyer, Alpern, Barton, DeMyer, Churchill et al. (1972); Jones &amp; Prior (1985)</td>
</tr>
<tr>
<td>Abnormalities of gait and posture</td>
<td>Bond (1986); Ornitz (1974); Vlinskiy, Damasio, &amp; Maurer (1981)</td>
</tr>
<tr>
<td>Parkinsonian symptoms such as akinesia/dyskinesia or difficulties initiating or switching movements, freezing, or stopping movements</td>
<td>Damasio, &amp; Maurer (1978); Maurer &amp; Damasio (1982)</td>
</tr>
<tr>
<td>Tourette’s disorder, including stereotyped movements, vocal, verbal and physical tics, and obsessive-compulsive traits</td>
<td>Comings &amp; Comings Realmuto &amp; Main (1982); Sverd Wing &amp; Attwood (1987)</td>
</tr>
<tr>
<td>Catatonia or catatonic-like phenomena including mutism, echolalia, repetitive movements, automatic obedience, odd hand postures, interruption and freezing of movements, increased slowness affecting passivity, and apparent lack of motivation and frenzy, excitement, or agitation</td>
<td>Ahuja (2000); Chaplin (2000); Hare &amp; Malone (2004); Kahlbaum (1973); Realmuto &amp; August Wing &amp; Attwood (1987); Wing &amp; Shah (2000)</td>
</tr>
</tbody>
</table>

Autism, apraxia, Parkinson’s disease, Tourette’s disorder, and catatonia comprise clusters of symptoms diagnosed through behavioral observation. The coincidence of symptoms does not necessarily denote one particular etiology. However, examination of the similarities of symptoms among these various syndromes may assist us in understanding aspects of autism that present challenges to people in communicating, relating to others, and participating in typical activities. We are interested in understanding the possible neurological basis for many symptoms of autism that are currently considered to be “behaviors.” In contrast, a social interpretation of these symptoms may leave people with the assumption that the symptoms with which people struggle are matters of choice, apathy, or learned behavior. For example, aggression during an episode of catatonic frenzy is viewed differently if the neurological aspects of the person’s experience are considered. Would punishment be used to change the behavior of a person with a recognized neurological symptom? Would criticism and dis-
couraging descriptions such as "laziness" be applied to a person in a catatonic stupor? Would a person with Parkinson's disease be scolded for reacting slowly when instructed to do something? Assumptions based on our social interpretations of symptoms may not always be helpful. We need a clearer understanding of people's experiences if we are to provide appropriate care and support that boosts self-confidence and is the product of collaboration rather than control.

Social interpretation of these symptoms is not unique to autism. Symptoms of sensory and movement differences in people labeled with developmental disorders may also be interpreted as a part of mental retardation or a learning difficulty without acknowledgment of the possible neurological basis for the symptoms. Rogers (1992) and his colleagues believe that unusual and abnormal movements of people labeled as mentally retarded or as having an intellectual handicap are often viewed as a side effect, a part of the retardation, or as a kind of self-stimulation. When people with movement disorders such as Parkinson's disease or Tourette's disorder show the same unusual movements, the behaviors are acknowledged for their neurological base and described in neurological terms; thus for one group, there is a social interpretation of behavior and for another group, there is a neurological description. Many of us have accepted without question the implicit message that unusual movements presented by people with autism are volitional and pleasurable. Table 8.2 illustrates the different labels given to behavior dependent on a person's diagnosis.

During the early 1990s, a small group of people, working both independently and as a team, were committed to increasing the understanding of symptoms in autism. One of the products of this synergy was an exploratory analysis using the symptoms of autism in a sample of published research accounts and the Diagnostic and Statistical Manual of Mental Disorders, third revised edition (DSM-III-R; American Psychiatric Association, 1987) to compare with symptoms of movement disturbance as categorized in the Modified Rogers Scale (Leary & Hill, 1996). Rogers (1992) and his colleagues have carefully examined movement differences as an integral part of some psychiatric and developmental disorders. They viewed the symptoms of catatonia, for example, as neurologically based movement disorders. The Modified Rogers Scale (Lund, Mortimer, Rogers, & McKenna, 1991) has been used to detail the motor disorders associated with catatonia, schizophrenia, and developmental disabilities.

The exploratory analysis presented by Leary and Hill (1996) helped us understand the wide range and complexity of symptoms of movement disturbance (see table 8.3). It was clear that at least some individuals labeled with autism have symptoms fitting most of the categories of the Modified Rogers Scale, suggesting the possibility that the core characteristics of autism may be based, in part, on the presence of neurological symptoms that affect sensation and movement. As documented in several disorders affecting sensation and movement, such as Parkinson's disease, catatonia, and Tourette's disorder, these symptoms frequently interfere with, and may even supplant a person's intentional movement.

Table 8.2. Differences in labeling

<table>
<thead>
<tr>
<th>People with movement disorders</th>
<th>People labeled with autism</th>
</tr>
</thead>
<tbody>
<tr>
<td>Akinesia</td>
<td>Noncompliance</td>
</tr>
<tr>
<td>Festination</td>
<td>Behavior excess</td>
</tr>
<tr>
<td>Bradykinesia</td>
<td>Laziness</td>
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<tr>
<td>Bradyphrenia</td>
<td>Mental retardation</td>
</tr>
<tr>
<td>Tics</td>
<td>Aberrant behavior</td>
</tr>
<tr>
<td>Obsessions</td>
<td>Autistic behavior</td>
</tr>
</tbody>
</table>

Because people with autism have grown up with these differences, their behaviors have been affected by the experience of sensory and movement challenges. As practitioners, we had relied upon the possible communicative intentions of a person's behavior as guideposts for providing them with support. In considering the possibility that some behaviors may not be intentional, even though they might be "communicating" vital information about an individual, we were faced with a new challenge. Movement and sensory differences may affect a person's to perceive, act, and respond accurately—that is, in a way that reflects his/her intention. Thus, our understanding of people's behaviors needed fine-tuning. We now had to consider that our intuitive interpretations of behavior needed to include the that the observed behavior was the result of difficulties organizing and regulating sensation and movement. In other words, "Behaviors may not be what they seem" (Leary & Hill, 1996, p. 44).

**FIRST-HAND EXPERIENCES OF INDIVIDUALS WITH AUTISM**

Within the last two decades, numerous individuals with autism have shared their unique experiences of living with autism resulting in a plethora of published first-hand accounts. Many professionals are seeking out and listening to these individuals to better understand this complex disorder (Cesaroni & Garber, 1991; Patterson, 2002a; Strandt-Conroy, 1999; Young, 2000). Individuals have been able to share their experiences through interviews, personal communication, and published accounts. These accounts come from individuals who can speak or type independently. In almost every first-hand account, individuals with autism report the experience of the stress of living in bodies that often do not work and move the way they want them to, resulting in extreme anxiety in their day-to-day lives.

A common theme that has emerged in the first-hand accounts fits in well with the dynamic systems model described earlier. That is, stress and difficulties with sensation and movement are described by labeled people as not necessarily having a cause and effect relationship. They suggest that the relationship would be better described as a causal loop, instead of a linear as "A causes B" or "B causes A." Instead, stress and difficulties with sensation and movement interact dynamically.
<table>
<thead>
<tr>
<th>Features of movement disturbance</th>
<th>Autism research</th>
<th>DSM III-R criteria for autism</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Posture</strong></td>
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<tr>
<td>Simple abnormal posture</td>
<td>Flexion dystonia: Maurer &amp; Damasio (1982); odd hand postures: Wing &amp; Attwood (1987), Walker &amp; Coleman (1976)</td>
<td>Failure to cuddle; odd hand postures</td>
</tr>
<tr>
<td>Persistence of imposed postures</td>
<td>Catalepsy: Realmuto &amp; August (1991)</td>
<td>Catatonic posturing</td>
</tr>
<tr>
<td><strong>Tone</strong></td>
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<tr>
<td>Gegenhalten (springy resistance to passive movement)</td>
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<tr>
<td>Mitgehen (anglepoise lamp-raising of arm in response to light touch)</td>
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<tr>
<td><strong>Abnormal movements, face, and head</strong></td>
<td>Myoclonic jerk of head: Walker, Coleman, Ornitz (1976); bruxism: Bebko &amp; Lennox (1989), Ornitz &amp; Ritvo (1976); mouthing: Walker &amp; Coleman (1976)</td>
<td></td>
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<tr>
<td>Simple sustained/grimace /spasmodic, not completely fixed</td>
<td>Disturbances in facial expression: Maurer &amp; Damasio (1982); grimace or rigidity for no apparent reason: Schopler et al. (1986), Walker &amp; Coleman (1976); decreased use of facial expression: Schopler et al. (1986)</td>
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<tr>
<td><strong>Abnormal movements, trunk and limbs</strong></td>
<td>Looks out of corners of eyes; avoids looking at adult in the eye: Schopler et al. (1986); eye-gaze/ocular abnormalities: Churchill &amp; Bryson (1972), Hutt &amp; Ounsted (1966), Mirenda et al. (1983)</td>
<td></td>
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<tr>
<td>Complex mannerism/stereotypylike; turning away, side to side, searching movements.</td>
<td>Looks out of corners of eyes; avoids looking at adult in the eye: Schopler et al. (1986); eye-gaze/ocular abnormalities: Churchill &amp; Bryson (1972), Hutt &amp; Ounsted (1966), Mirenda et al. (1983)</td>
<td>Facial expression and gesture is absent or minimal or socially inappropriate in form; lack of eye contact</td>
</tr>
<tr>
<td>Simple sustained/dystonia /abnormal muscle stretch and flex</td>
<td>Flexion dystonia: Maurer &amp; Damasio (1982)</td>
<td>Arm flapping; abnormalities of motor behavior; gesture is absent or minimal or socially inappropriate in form</td>
</tr>
<tr>
<td>Complex mannerism/stereotypylike</td>
<td>Motor stereotypies: DeMyer et al. (1972), Hutt et al. (1965), Kern et al. (1984), Maurer, &amp; Damasio (1982), Meiselas et al. (1989), Ornitz &amp; Ritvo (1976), Ornitz (1974), Ornitz &amp; Ritvo (1968), Ritvo et al. (1971), Sorosky et al. (1968), Walker &amp; Coleman (1976)</td>
<td>Motor stereotypies include peculiar hand movements, rocking, spinning, dipping and swaying movements of the whole body</td>
</tr>
<tr>
<td>Abnormal ocular movements</td>
<td></td>
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<tr>
<td>Increased blinking</td>
<td></td>
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<tr>
<td>Decreased blinking</td>
<td></td>
<td></td>
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<tr>
<td>Eye movements; to and fro, roving, conjugate</td>
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Table 8.3. (continued)

<table>
<thead>
<tr>
<th>Features of movement disturbance*</th>
<th>Autism research</th>
<th>DSM III-R criteria for autism</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Purpose movement</strong></td>
<td></td>
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</tr>
<tr>
<td>Abruptness/rapidity of spontaneous movements; suddenness quality</td>
<td>Bradykinesia: Maurer &amp; Damasio (982); dyspraxia: DeMyer (975), DeMyer et al. (972), DeMyer et al. (981), Jones &amp; Prior (985)</td>
<td></td>
</tr>
<tr>
<td>Slowness/feebleness of spontaneous movements; weak, languid, labored</td>
<td>Spatial/logic symmetrizing and ordering: Frith (1971), Kanner (943), Prior &amp; Hoffman (990), Prior &amp; Macmillan (973); obsessive-compulsive behaviors: Baron-Cohen (1989), Frith (971), Kanner (943), Maurer &amp; Damasio (982); object exploration through proximal senses: Frith &amp; Hermelin (969), Goldfarb (956), Masterton &amp; Biederman (983), Maurer &amp; Damasio (982), Ornitz (974); Sorosky et al. (968); self-injurious behavior: Favel et al. (978), Gabony (911), Gedye (989), Guess &amp; Carr (991), Rolder &amp; VanHouten (985), Walker &amp; Coleman (976), Winchel &amp; Stanley (1991); persistent strange or peculiar body movements despite attempts to discourage them: Schopler et al. (986); perseveration: Chess (972), Frith 0970, 1971), Hoffman &amp; Prior (982), Kanner (943), Maurer &amp; Damasio (982)</td>
<td>Abnormalities of motor behavior; self-injurious behavior</td>
</tr>
<tr>
<td>Exaggerated quality to movements; nourishes/flurries of adventitious movements</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Iterations of spontaneous movements; gesture, mannerism repeated</td>
<td>Loss of associated movements: Bartak et al. (975), DeMyer et al. (972), Maurer &amp; Damasio (982), Vlensky et al. (1981)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Brandykinesia: Maurer, &amp; Damasio (982)</td>
<td></td>
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<td></td>
<td>Gait disturbance: Bond (986), Hutt et al. (964), Maurer &amp; Damasio (982), Sorosky et al. (968), Vlensky et al. (981); toe walking: Schopler et al. (986)</td>
<td>Walking tiptoe; jumping</td>
</tr>
<tr>
<td></td>
<td>Slow/shuffting Manneristic, bizarre</td>
<td></td>
</tr>
<tr>
<td>Gait</td>
<td>Echopraxia: Carr (979), Konstantareas (985); hypermimic: Bartak, Rutter, &amp; Cox (975), Curcio &amp; Prerchia (978), DeMyer 0975, 1976), Rutter (974)</td>
<td>Repetitively mimics actions</td>
</tr>
<tr>
<td>Exaggerated associated movements</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reduced associated movement</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Speech</td>
<td>Dysprosody: Baltaxe (1981), Ornitz &amp; Ritvo (968); poor speech volume modulation: Baltaxe (1981), Ornitz &amp; Ritvo (968); abnormal tone, rhythm, volume: Schopler et al. (986)</td>
<td>Abnormal speech melody</td>
</tr>
<tr>
<td>Aprosodic; abnormal rate, volume, intonation</td>
<td>Mutism: Curcio (1978), Konstantareas (985), LaVigna (977), Maurer &amp; Damasio (982), Ornitz &amp; Ritvo (968), Ritvo et al. (1971); lack of communicative initiations: Curcio (1978), Loveland &amp; Landry (986), Maurer &amp; Damasio (982), Mundy et al. (990), Ornitz &amp; Ritvo (968), Prizant &amp; Wetherby (985), Rapin (987), Ritvo et al. (971)</td>
<td>Language may be totally absent</td>
</tr>
<tr>
<td>Mutism</td>
<td></td>
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</table>
## Table 8.3. (continued)

<table>
<thead>
<tr>
<th>Features of movement disturbance</th>
<th>Autism research</th>
<th>DSM III-R criteria for autism</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indistinct/unintelligible speech; mumbling, poor articulation, nonsocial speech</td>
<td>Use of jargon: Schopler et al. (1986); vocal, verbal tics: Comings &amp; Comings (1991), Realmuto &amp; Main (1982), Wing &amp; Attwood (1987)</td>
<td>Delayed or immediate echolalia; verbal stereotypes including repetition of words, phrases</td>
</tr>
<tr>
<td>Overall behavior</td>
<td>Catatonic excitement: Wing &amp; Attwood (1987); extreme response to minor environmental changes: Campbell et al. (1979), Geller et al. (1981), Kanner (1943), Ornitz &amp; Ritvo (1966), Prior &amp; Macmillan (1973); hyperkinesis: Sorosky et al. (1968); explosive/violent movement episodes: Campbell et al. (1972)</td>
<td>Catatonic phenomena, particularly excitement or posturing; aggressive behavior</td>
</tr>
<tr>
<td>Marked overactivity</td>
<td>Hypomimesis: Bartak et al. (1975), Curcio (1978), Curcio &amp; Piserchia (1978), Dawson &amp; Adams (1984), DeMyer (1975), DeMyer et al. (1972, 1981), Schopler et al. (1986); almost never initiates: Schopler et al. (1986); almost never responds to the adult: Schopler et al. (1986); catatonic stupor: Realmuto &amp; August (1991); decreased responsiveness: Lovaas et al. (1991), Ornitz &amp; Ritvo (1968), Prizant &amp; Wetherby (1985), Rapin (1987)</td>
<td>Indifference to affection or physical contact; no or impaired imitation</td>
</tr>
<tr>
<td>Marked underactivity</td>
<td>Excessive compliance/automatic obedience</td>
<td>Oppositional behavior; aversion to physical contact</td>
</tr>
<tr>
<td>Other: negativism</td>
<td>Ritualistic behavior: Frith (1991), Kanner (1943), Maurer &amp; Damasio (1982), Prizant &amp; Macmillan (1973)</td>
<td></td>
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<tr>
<td>Other: engages in rituals</td>
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Reprinted with permission from Leary & Hill (1996).

Movement features represent items adapted from the Modified Rogers Scale (Lund, Mortimer, Rogers, & McKenna, 1991).
Stress can play a significant role in a person’s ability to organize and regulate actions and postures. It can also affect speech and language, as well as emotions, perceptions, and memories. Often stress can cause unusual sensations and movements to escalate (Brenner, Friedman, & Merrit, 1947). Some individuals report that they may feel physically unaware of their body and movements (e.g., Blackman, 1999; Hale & Hale, 1999; Williams, 1996a, 1996b, 2003). Williams (1996b), for example, reported how stress affected her movement, causing her to feel pushed beyond her limits. She described three involuntary situations that might occur during an episode of stress. She might become dissociated, thus causing her to lose all conscious connection with her movements. Or she might shut down completely, causing her movement to become involuntarily "frozen." She likened this to the feeling of "test anxiety." Finally, overload from stress might cause her painful sensory hypersensitivity. She also described the feeling of stress spiraling out of control, taking her to a point where she was completely unaware of her body in space.

Stress can be immense when sensations and movements are unreliable and unpredictable. Imagine having to cross the street. You know that you only have a certain amount of time to get to the other side. Knowing in the back of your mind that you might become stuck and unable to move when you are in the middle of the street would cause a great deal of anxiety and stress. If this stress causes you to avoid such situations, it will have a direct impact on your daily activities.

In the following section, first-hand accounts are used to explore the complexity of the dynamics of autism, stress, sensation, and movement differences.

**Experiences of Stress and Anxiety**

Donna Williams has written numerous insightful books describing her experience of autism. Recently, she published *Exposure Anxiety: The Invisible Cage* (2003). Similar to conditions such as agoraphobia and reward deficiency syndrome, Williams defined exposure anxiety as a "self-parenting survival mechanism, an intense often tic-like involuntary self-protection mechanism that jumps in to defend against sensed 'invasion'" (p. 10). Williams went on to describe it as "feeling your own existence too close up, too in your face" (pp. 10-11), like a "vulture" that was watching and waiting, affecting every moment, especially when the situation was stressful: "The more I wanted to say or show something, the more my own Exposure Anxiety was tuned in, hanging on my every expression. My body, my facial expression, my voice and my words were pulled about by some wild horse inside of me. I’d want to say I was sad, my face would be beaming. I’d want to sit calm and still and enjoy a sense of company, my body would be propelled into wild diversion responses demonstrating discomfort and hyperactivity. I’d try to tell someone I liked them and swear at them, try to show caring and be compelled to do something to repel them" (p. 103).

Struggling against the will of her body was something that Williams had to deal with on a daily basis. Williams also described the complex self-protective responses often necessary to cope. She raised interesting questions about how exposure anxiety affects movement and how these differences can appear so odd:

Why can someone with Exposure Anxiety be expressively and naturally laughing out loud out in the back garden but somehow "stuck", compliant, or performing when in front of others? Why they can’t get together to make breakfast once you are up, or run the bath, or get dressed, but seem to do a whole range of things which might prove they were capable of these? Why might someone with Exposure Anxiety be able to initiate communication with their own reflection and yet unable to respond as themselves when shown affection? Or be able to initiate an activity, but when you try to initiate exactly the same activity with them, appear uninterested, distracted or disowning? Why, although they have an ability, do they appear to freeze and become incapable in front of others or when asked to perform a task on command? (Williams, 2003, pp. 21-22)

Having all these questions and few answers lead to a number of emotions, including stress and anxiety. Many individuals with autism report that fear, anxiety, and stress are the dominant emotions of their every day life.

**Challenges in Organizing and Regulating Actions**

Sensory and movement differences can have a direct impact on the individual’s action. This can involve difficulties initiating and executing movements. It can also affect difficulties with stopping, combining, and switching movements. Organizing and regulating sensory information and movement to perform tasks may be frustrating for people with these differences. Extreme emotions can cause the individual to become stuck, unable to stop a movement. Sean Barron (Barron & Barron, 1992) recalled, 'All I wanted was to be like the other kids my age. I felt as if I was weird and strange on the outside, but inside I wasn’t like that. The inside person wanted to get out and break free of all the behaviors that I was a slave to and couldn’t stop’. (p. 181). For many of these individuals, as for Sean, simple movements can lead to repetitions or perseveration, even if the individual wants to stop the movement.

Some individuals report that they get stuck and unable to initiate movement. Williams (1996b) described this experience as a "suffocating and frightening experience of helplessness" (p. 171). Williams (1996a) recalled, ‘found myself physically stuck and physically disconnected. I struggled to ‘remember’ how to cross the room or open a drawer, but I was now trying to remember with my body and my body had little memory of moving as me. Inside of me I was thinking, Come on, leg, you know what to do. But it was like my body couldn’t hear me, like I had no body-memory’ (p. 99).
It is little wonder that the fear of being stuck like this in public would cause these individuals to live in a nearly constant state of stress and panic. When asked if he feels stress when he is stuck, Charles Martel Hale, Jr. (Hale & Hale, 1999) replied, “Yes. It feels like I am doing a marathon just to move” (p. 35). Feeling disconnected from your body has been likened to being a puppet on strings with someone else in control. Williams (1996a) stated, “If not for a sense of humor I might have killed my body outright in retaliation” (p. 89). Often, Williams would want to go in one direction, but her body would take her in another. Her body seemed to be off on a track of its own. This complete lose of control of the body may cause frustration, anxiety, and stress within these individuals. Charles recalled that his movement disorder is most apparent when he is unable to respond to someone or something in an appropriate manner (Hale & Hale, 1999). Although his intelligence told him how to respond, his body would not always follow along: "For instance, when I should be smiling, sometimes I know that I am not smiling but may even frowning. This causes me a great deal of pain-and makes me look as though I am not comprehending when, in fact, I am crying to respond in an appropriate manner" (p. 32).

Sean Barron (Barron & Barron, 1992) recalled the intense frustration and stress when he was unable to perform fine motor tasks, such as buttoning or tying his shoes: "Many times I ripped the buttons off my shirts and broke my laces because I was so furious with the damn things when they refused to work" (p. 200). Temple Grandin recalled feelings of stress when being asked to perform two motor tasks at the same time: "Getting all the parts to work together is a monumental task" (Grandin & Scariano, 1986, p. 26). Transferring the knowledge of the movement to actual performance of the task left these individuals completely exhausted. Jim, a participant in a study by Cesaroni (1990), reported that combining and synchronizing movements was as difficult as trying to make your eyes blink at opposing times.

Individuals with autism say that knowing that others judge them by their actions causes them pain, stress, and frustration. Charles is constantly stressed by the fact that how he moves within his environment affects the way he is perceived: hope people will begin to understand that appearances do not always indicate how a person thinks and responses do not show our abilities . . . I know that it is difficult for anyone to understand unless he has the problem himself. If people could give us a chance in life to prove ourselves, many people would be happier and feel a part of society and not just misfits" (Hale & Hale, 1999, pp. 32-33).

Experience of Perceptual Differences

Perception can also be greatly affected through this loop of stress and movement differences. Williams (1996a) recalled that escalators provoked dizziness and loss of awareness of where her body was in space. For Grandin (1995), various stimuli such as a telephone ringing or the arrival of the mail, could cause a full blown stress attack. Tito Rajarshi Mukhopadhyay (2000) found that open space was a stressor for him. Open space made him feel as though his body was being scattered. Tito's reaction to this stressor would be to tantrum. This fear of open spaces caused him stress for many years.

These individuals tell of experiencing differences in sensory integration where information from one sense may blend with another sense. For some individuals, labeled people as well as those who are not, this may be pleasant. For others it is a stressor. This blending of senses is known as synesthesia, which may result in hearing colors, seeing music, and tasting objects (Ramachandran & Hubbard, 2003). Jim, a participant in Cesaroni's study (1990), described his experience with synesthesia: "Sometimes the channels get confused, as when sounds come through as color. Sometimes I know that something is coming in somewhere, but I can't tell right away what sense it's coming through" (p. 74).

Other individuals describe an inability to process two or more sensations that are occurring at the same time. Rand (as cited in Strandt-Conroy, 1999) described this difficulty combining different kinds of sensory input as, "sometimes only one thing can go in at one time. So the sight could go in first, then fade out because the sound is coming in. When the sight fades only the sound is left, it is the only information the person is getting, which makes it sound louder because it is all he can focus on" (p. 79).

Some individuals with autism report that difficulty with organizing and regulating sensory information causes them to have unusual responses to sensations of hearing, vision, touch, taste, and smell. Judy Barron (Barron & Barron, 1992) described many of the sensory experiences that brought stress into her son Sean's life: "The one thing that did hurt him was having his scalp touched; when I washed his hair he squirmed and cried out, trying to push my hands away. Though I was as gentle as possible, it was obviously painful to him. It was even worse when I brushed his hair-he screamed ‘OW!' over and over, wrenching away from me" (p. 34).

Sean noticed that these sensory experiences made him different from others, causing him anxiety every day (Barron & Barron, 1992). He described sitting in a bathtub as painful. He was extremely sensitive to the squishy feeling around him: 'When they insisted I 'sit right,' it only compounded the problem. I had no choice-I had to sit in an unnatural way, so baths were a trying experience. Also it made me feel that there was something wrong with me because I had to sit that way" (p. 96). Even a bath, a very relaxing sensation to many people, caused Sean extreme discomfort and distress.

Temple Grandin (Grandin & Scariano, 1986) was very clear about the effect of sensory overreactions in her daily living: "The clamor of many voices, the different smells, perfume, cigars, damp wool caps and gloves—people moving about at different speeds, going in different directions, the constant noise and confusion, the constant touching, were overwhelming" (p. 21). Grandin also
described how these overwhelming reactions would often cause her to act out: would invariably react by hitting another child or by picking up an ashtray or anything else that was handy and flinging it across the room” (p. 20).

From time to time, we all experience difficulties with a repetitive thought, but people with sensory and movement differences report unmanageable repetitive thoughts. Kathy, another participant in the Strandt-Conroy (1999) study described how intrusive thoughts could lead her to distraction and stress:

I think in some situations it’s just harder for me not to have intrusive thoughts. Some autistic people, they say, block things out or they shut things down or whatever. My mind doesn’t think - I’m not able to stop an intrusive thought or block something out unless it’s something really, really, really mild - but if it’s severe, it all comes in and there’s no way I can stop it. I’m not able to tune out anything. Intrusive thoughts would be nonsense syllables or something. I don’t understand why this is - but if I was trying to study a foreign language or if I tried to study anything with odd-sounding words, I’d get nonsense syllables and stuff would pop in my mind and anxiety. It doesn’t make a bit of sense. I don’t why it happens. (pp. 125-126)

Other individuals described their defenses against an environment that caused them so much stress. Lucy Blackman (1999) described how she had to accommodate to perceptual inconstancy: "On the good days, my world was one of time and 'feeling' and light and movement all in one, but fear or other unpleasant sensations fragmented my surround, so I relied on activities such as swaying, humming and running in circles, which defended me against uninterrupted exposure to my sound-environment" (pp. 34-35).

Blackman (1999) went on to describe the behaviors she used to accommodate her sensitivity to overwhelming auditory stimulation: "Because other people’s sound processing was alien to me, I had no idea that sound should not be like a pressure-cooker lid. I put my hands to my ears for loud noises. but the continuous clamor of everyday life was only relieved by movement. Even in the classroom there was visual stimulation and noise, which combined with my own breathing and a buzzing effect that I think was my own inner ear. I rocked, swayed and scampered. even though I knew how to sit in one place and that it was expected of me" (p. 51).

Donna Williams (1996b) told how constant adaptations and accommodations to unusual sensory experiences can be emotionally and mentally stressful, especially after years of these experiences: "After 10, 20, or 30 years, people with systems integration problems, due to whatever reason, have pretty much developed adaptations to their difficulties which might be mentally and emotionally difficult to change. Also, in correcting an underlying problem someone has taken many years adapting to the impact of these changes upon one’s identity and personality may sometimes be more than the mind or emotions can handle in too big a dose" (p. 67).
On the other hand, many individuals report that they want to speak, but combining all the actions appropriately is often an impossible task. Lucy Blackman (1999) experienced this in many daily interactions: "My speech really just bulges out of my mouth like a balloon, and the real thoughts in my head just keep on a direct line. The direct line and the balloon are related, but they do not correspond, and the more the balloon bulges, the less sense it makes, until it bursts, leaving nearly all my thoughts scattered, and me wild with anger and shame" (p. 135).

Thomas McKean (1994) described his experience with speech: "There are, on occasion, still times when I want to talk, but I can’t. I can try and try and try, but I can’t talk. There is a fear holding me back. I do not know what it is I am afraid of, I only know that it is a feeling of fear unlike any other feeling of fear I have ever known. It is not that I do not want to talk, it is that I am unable to at that moment" (p. 39).

Donna Williams (1992) reported a similar experience of fear regarding communication: "The anxiety of my inner battle was becoming unbearable. I could say words but I wanted to communicate. I wanted to express something. I wanted to let something out. The anxiety would have been so easy to give in to; whereby I would again lose all awareness of self and my surroundings" (p. 19).

Williams (1992) described increased difficulties finding words and initiating speech as her emotional intensity increased: "At worst, the stress of direct, emotionally loaded communication either blocks the brain’s ability to retrieve all or any of the words needed to speak a fluent sentence or won’t allow the process of articulation to begin, leaving the words echoing within the speaker’s head. The frustration of this can lead, as I described, to the deafening scream of frustration that may not get out of the speaker’s mouth" (p. 208).

And, Lindsay, as reported in Strandt-Conroy (1999), stated how he accommodates himself to the stress of retrieving and initiating speech: "What I do is think in ideographs or thought-pictures and then translate them into speech as I go, which normally gives my speech a slight hesitancy, and the degree of this hesitancy is a very good stress-gauge. When I am under a good deal of stress my speech becomes markedly hesitant, but when I am comfortable in a situation then the hesitancy is something that only I can notice" (p. 116).

Routines, Rituals, and Perceptual Motor Habits
Perceptual motor habits are those skills that a person has acquired through extensive experience. Perceptual motor habits allow us the freedom to move, think, and talk without conscious attention to performing a skill. Sensory and movement differences can also have an effect on a person’s ability to establish and sustain perceptual motor habits. For some people with sensory and movement differences, it is difficult to establish perceptual motor habits or, once established, the perceptual motor habit must be performed in the same way each time. A lack of flexibility in this skill base may mean that combining the skill with other events or in different settings forces the person to use conscious thought to perform the skill. People report that enormous effort is needed to think about moving in the most mundane ways. Geneva, a participant in a study by Strandt-Conroy (1999), pointed out how using conscious thought for movement and perception brought increased stress to her everyday life:

People don’t realize the major problem that nobody ever sees or realizes is how much conscious thinking we have to do just to function. Walking takes thinking. So if I am walking and you ask me a question I could trip or I could mess up the sentence and put the wrong word in. Or have to stop and say what did you say? I can walk with my girl friend down the street and carry on a conversation as long as she is right there but I have to look down at the sidewalk. I have to keep track of where the sidewalk is and where any obstacles are and all that stuff and sometimes if I have to keep walking and I feel like I am going to blow any second I make sure the path is clear ahead of me and close my eyes and continue walking. (p. 124)

Often people establish routines as an accommodation to difficulties with perceptual motor habits. When fewer aspects of a task vary, they report that less effort is needed to perform the task. Rand reported in Strandt-Conroy (1999) that routine and sameness assist him in finding meaning in his environment:

Some people who are different like routines. They like to know what is going to happen next, and they like it to be the same thing that happened last time. When information, which is sights, sounds, tastes, smells, and touches, goes into their head, if it is information they’re used to because they’ve had this information before, it can go into their head on the same pathways to the same places and get processed the same way as before. So if someone learns that a picture hanging on a wall usually hangs straight, if they see a picture hanging straight, that information is easy to process because it is the same as before. It goes along the same pathways to the same places, maybe those places are checkpoints that decide what the information means. Like it is flat, it is colorful, it is scenery, it is hanging straight on the wall. So it gets to the same result. It is a picture. But if a picture is hanging crookedly, it might start being processed along the same pathways to the same checkpoints, but then it might suddenly stop at some checkpoint because something is not the same as before so some checkpoint made a different decision about the information. Then the information might go off that pathway along different pathways, and whenever different pathways have to be used they could turn out to be bad ones, which means the information could just stop completely or get backed up or go off on wrong pathways. So it might never get to the same result, that it is a picture, or it might finally get there, except that it took longer and was a lot more work. (pp. 126-127)
and hear the conventional expressions of emotion, we may assume the person does not feel emotion. Kathy, a participant in Strandt-Conroy (1999), reported feeling as though she was on an emotional roller coaster. Barbara, a participant in the same study, reported that there was never a time when she felt completely free of concern about emotions. Others report similar challenges in controlling emotions, expressing emotions, identifying emotions, and changing emotions. Barbara explained: “I think I’ve had times when I wasn’t able to express how I was feeling and sometimes it was hard to experience my feelings directly. And one of the biggest problems was that I tried to express how I felt and people just didn’t understand; my feelings were just so much different than another person that they just simply disregarded it” (Strandt-Conroy, 1999, p. 105).

Not having her feelings understood or recognized could trigger intense anxiety for Barbara. This kind of stress is reported by the participant in Jolliffe, Lansdown, and Robinson (1992) who stated, “It occurs at any time, but always when I know I have to go somewhere stressful. Sometimes the pain is so bad that my body becomes stiff and then I am unable to move” (p. 14).

There is also an assumption that people with autism do not want to interact with others. People’s reactions to behaviors they do not understand can lead to isolation for many people with autism. Barbara described this in the Strandt-Conroy (1999) study as,

I had no meaningful relationships with anybody. An autistic person has to jump through hoops in order to be accepted by others. I wasn’t good enough for anybody. They didn’t like my behavior and I couldn’t make friends very good—there was nobody around I could be myself with because the only people were involved with me were those who were paid to make me behave. There was nobody I knew then that would let me be myself. There was nobody who would like me as I was. I felt unwanted. I would be told ‘people won’t accept you if you do this—people won’t accept you if you do that.’ There’s no way I could’ve made myself quiet enough and calm enough and attractive enough to make people accept me. It just wasn’t in there” (pp. 109-110).

Although many individuals report that they have challenges when it comes to emotions, it is not an absence of interest in emotional interaction. They continue to try to relate to others. Jim, in the Cesaroni (1990) study, shared his perspective regarding the common assumption that people with autism lack empathy: “Someone who has much better inherent communication ability than I do but who has not even taken a close look at my perspective to notice the enormity of chasm between us tells me that my failure to understand is because I lack empathy” (pp. 94-95).

Cesaroni (1990) pointed out that “Jim raised an interesting question which merits consideration: if a large amount of effort and energy is devoted in trying to understand others’ perspectives, does Jim have less empathy than those people who not only do not understand him, but who do not even notice they do not understand him?” (p. 95).

Concluding Remarks on First-hand Accounts

The first-hand reports from people with autism provide us with powerful insights into how stress affects their symptoms and how the appearance of their symptoms is affected by stress. People need support that acknowledges their differences, accepts them the way they are, and provides them with the tools they need to learn and to cope with a world that may often be overwhelming. Donna Williams (2003) comments on treatment instruction and education that emphasizes “normality” while ignoring a person’s true nature: “If you gain expression or skills that are not connected to self, they represent feels like a facade [sic], a cardboard reality, a parody. It can work for survival if you are really pushed, but it is not really the kind of stuff you can use as a basis for an enjoyable existence because it’s disconnected from any internal emotional intrinsic reward. Such apparent ‘success’ may feel intensely alienating and isolating” (p. 290).

Understanding how sensory and movement differences affect everyday existence is an important step. Finding ways to assist a person to accommodate and to promote body movement control and awareness are also key. Throughout this discovery process, we need to rethink commonly held assumptions about these individuals in order to listen to them and provide them with the appropriate support, presuming competence and seeing them as complete human beings, not as individuals with something missing. The voice of the labeled individual must be included in our new understanding of autism and sensory and movement differences. On this basis, we can begin to address them as people who need unique accommodations and support.

Stress, sensation, and movement have a direct impact on daily living. Speaking, facial expression, action, and emotion are all organized and regulated by sensation and movement. A person’s emotional state and the level of intensity of emotions, whether these are positive or negative in nature, may make the balance between inhibition and activation more difficult to achieve (Brenner et al. 1947; Leary & Hill, 1996; Maurer, 1992, 1993). For many, unusual sensations and movements are less pronounced and less problematic when a person is distracted (Brenner et al. 1947). Distraction may be an effective support strategy for some people and in some situations. The following section provides more accommodations for individuals experiencing sensory and movement differences.

ACCOMMODATIONS

We draw on the historic works of Aleksander Romanovich Luria, a Russian psychologist and neurologist, in using the term “accommodations” to describe those supports that temporarily assist a person with difficulties in sensation and movement control, in participation, and behavior regulation. Luria (1932/1976) details many accommodations devised by or for individual people in his book, The Nature of Human Conflicts. After years of research working directly with
people challenged by differences in their abilities to organize and regulate sensation and movement, he wrote of the need for people to develop accommodations or substitutions for the usual methods of motivation that may not be available to people during an episode of movement disturbance. Years later, Oliver Sacks (1990) credited Luria for his understanding of the importance of accommodating rather than battling such problems by force of will. Sacks used a metaphor to describe the process of accommodating to the challenges of organizing and regulating sensation and movement: "Neither defiance nor denial is of the least use here: one takes arms by learning how to negotiate or navigate a sea of troubles, by becoming a mariner in the seas of one's self. 'Accommodation' is concerned with weathering the storm" (p. 265).

Accommodations are personalized strategies that assist in temporarily overcoming differences in learning style, sensory integration, and/or movement. We all use accommodations to temporarily compensate for difficulties we may have in starting, executing, and stopping movements. We may also need accommodations for combining and switching behavior, thoughts, perceptions, speech, language, memories and emotions. Some common accommodations include the use of gesture, touch, and rhythm. Also, behavior rituals, sequences, and changing the aspects of tasks have proven effective, as well as visualization, music, and other strategies. These accommodations will be different for each person and the person's need for accommodations may vary from day-to-day or hour-to-hour. Accommodations may be effective for a time and then lose their effectiveness for a person. It is always a good idea to have a "menu" of possible accommodations for a particular person, considering alternative accommodations when needed.

Accommodations cannot be explained in a developmental framework. That is, for most accommodations there are no prerequisite skills, no linear progressions. Although some factors may seem to play a more central role in assisting a person to accommodate, it is often an array of accommodations that allow skills to emerge. Given appropriate supports from experience, other people, and the environment, a person may be able to demonstrate competencies that have not been evident before. Broderick and Kasa-Hendrickson (2001) provide a thoughtful qualitative analysis of one teen labeled with autism and his acquisition of reliable speech at age 13. The authors viewed this young man's progress as reflecting a dynamic systems model for development, as described by Thelen and Smith (1994), rather than the more traditional linear model for development. Broderick and Kasa-Hendrickson note that no single component of the array of supports for speaking appeared more important than another and his development did not follow the usual expected sequence of learning to "listen, speak, read, write" (p. 23). Instead, his emerging speech "was a complex, dynamic, and fluid expansion of [his] expressive communication system, a system in which he continues to integrate both speech and typing in complex and novel ways" (p. 22). They emphasized that the whole experience of communicating and receiving support to speak was greater than the sum of the individual parts.

Labeled people often devise their own accommodations, without the assistance of others. For example, people who have difficulty passing through a doorway or making other transitions, such as from wood flooring to carpet, report that taking a step backward during the transition may ease their ability to move and avoid their getting "stuck" in a doorway. Others may wave or flap to help propel themselves through. Some of the accommodations that people have devised for themselves may appear unusual or bizarre to others. Family and professionals may recommend that a person change a particular accommodation for a specific reason (e.g., because the accommodation causes damage to or hurts self or others or limits a person's access to many environments). It is, therefore, critical to recognize the possible function that an unusual behavior may serve and to provide alternative accommodations to fulfill that function.

Accommodations are strategies that people use to find the balance they need to regulate sensation and movement when the natural, unconscious mechanisms are not enough (Donnellan & Leary, 1995). Accommodations do not necessarily replace instructional strategies but may be used to personalize more conventional programs. The following accommodations have been developed by individuals who exhibit movement differences and by the professionals and family members who support them (Donnellan et al. 2003; Williams, 1992; 1994; 1996a; 1996b; 2003). The descriptions of accommodations we provide here are not exhaustive, as this is meant only to be a brief introduction. Nonetheless, because accommodations are so personalized, there is no limit to the style and number of accommodations that can be created. There are as many accommodations as there are people and situations to use them (Donnellan & Leary, 1995). Although these accommodations are in no way a cookbook or how-to guide, we hope they will spark interest and creativity when it comes to providing and creating accommodations.

Accommodations for Organizing and Regulating Actions

People often experience difficulties initiating, executing, stopping, combining, continuing, and switching actions and postures, including movements of the whole body, facial expression, gestures, and head movements. They and their families or caregivers often work out ways of supporting movement that is functional, timely, and done with less effort. These accommodating strategies can boost a person’s confidence and may reduce stress that results from unreliable movement.

Use of Touch Some individuals with autism have reported the use of touch as a very useful accommodation. For some, a gentle touch to their arm, shoulder, or back can help initiate an action. The film Awakenings, based on the book by Sacks (1990), illustrates how one patient is able to stand and move only when
attention, such as touching an arm or hand, and waiting for attention before speaking.

**Use of Rhythm** Rhythm is a well-known facilitator for most people. In fact, many couples credit their ability to dance well together for the onset of their relationship. Using a rhythm, tempo, or any rhythmic sound can be especially helpful during transition times. Moving with another person in rhythm can be used to help initiate action for people with movement differences. Sacks (1990) reported that one of his patients was able to initiate action when he walked with her. She explained that she felt the power of his walking, which assisted her in her own movements. Some individuals report that performing a task to a certain tune or rhythm can often help as well. Music is often a preferred activity for people labeled with autism. Children who show little imitative ability or emotional expression can be seen to jump, dance, and smile with a favorite television character dancing to music. The use of music as an accommodation must be personalized. Sacks (1990) relates that one patient only moved to music that "moved"—some people hum or sing softly to themselves while working or playing. Rhythm can be found in many activities, including reading aloud from a storybook or reciting poetry. Some individuals comment that slight sounds in the environment, such as the sound of a clock ticking, can provide the necessary tempo. Ralph Maurer (1993), a psychiatrist specializing in understanding people labeled with autism, has noted that people who rock their bodies, walk with skating-type movements, or otherwise rhythmically may be trying to compensate for difficulties in establishing a rhythm for movement. He recommended that supporters pay close attention to the rhythm that people use when rocking. Matching this rhythm may provide a way for a supporter to enhance a relationship with a person.

**Use of Imagery** Many people in sports, business, and health have used imagery-based programs successfully. June Groden and her colleagues, in collaboration with Joseph Cautela, successfully adapted covert conditioning procedures for people with special needs that are based on visualization and imagery (Groden, Cautela, LeVasseur, Groden, & Bausman, 1991). Imagery and visualization may help some individuals to get started or stay with an activity, as well as to cope with possible disruptions in specific situations. Grandin (1995) reported how she easily thought in pictures; her thoughts were similar to that of a film. Actual visual representations, such as photographs or drawings, are often used to establish an image. For other people, imagining a detailed scene may be enough. Luria (1932/1976) reported that his patient, Ivan, had great difficulty getting out of his bed in the morning. Ivan used a combination of visual representation and imagery to accommodate to this difficulty. He painted a tree next to his bed so that he could arise in the morning by imagining himself climbing the tree.

In addition to imagery-based accommodations, many people use things that they are able to see or read to help accommodate. Some move well when they see sequences or steps that are written in words or represented in drawings. Others have told us that looking toward a destination or watching someone else move can provide the support they need. The placement of objects can be a useful accommodation, for example, providing the motivation to do a task when the tools are assembled and visible. Objects can be used to cue an established skill or perceptual-motor habit, such as seeing the dishwasher as a cue to dry and put away the dishes. Even a simple gesture or facial expression may provide the needed trigger for an individual. Remembering the last time the sequence was performed may help some individuals perform it again. Specifically going through the steps of the action in one’s mind prior to an event may also be helpful.

**Use of Words** There are many ways to use spoken or written words as accommodations. In this chapter, we cover a few verbal accommodations related to organizing and regulating actions and behavior that may be useful for some individuals.

The ritualized use of key words, or “catch phrases,” may be a helpful accommodation for some people. People report that hearing the words said in a specific tone of voice or from a specific person may help them initiate an action or maintain self-control. Saying these words softly or silently to oneself or listening to a recording of a specific voice may be used as an accommodation. One person mentioned that carrying a short note in her pocket helped her to get through difficult times.

**Use of Preparation** Preparation for change and transition may present a special challenge for people with unusual sensory and movement abilities. Transitions are often reported to be times of uncertainty; many people are aware that minor changes will stretch their flexibility and tap their energy. Some people report that they have a less stressful experience if a situation is explained from their own point of view in advance. Perhaps because some people need more than the usual amount of time for organizing and regulating their actions and emotions, they appreciate getting information on events well before the event is to occur.

Many people have experience with stories told to them during a quiet and calm time and which relate to future events. Carol Gray (1994, 2000) has assembled many good examples of social stories that provide guidelines for using stories more effectively. It is helpful to know details such as who, what, when, where, and how long. These stories may be in written form or spoken. When a story is repeated, some people appreciate the sameness and want to hear the same words, while others like the story to contain other words and new details. People frequently report that the best situation for listening to these kinds of details is one that does not require looking directly at the speaker or repeating the information provided. For some, tests of comprehension, such as answering questions about the information, are not helpful or necessary. Other people like
the opportunity to repeat back the information in order to use it for themselves whenever needed. Preparation for change may reduce the anticipation by supporting a person’s confidence and assisting in planning.

Use of Prompts The use of verbal prompts to support a person to initiate or complete a task may be an appropriate accommodation for some people, in some situations. Experience and reports from others, however, indicate that many people become unable to perform a task without those spoken prompts. When a person learning a task that should be done independently (e.g., getting dressed, showering), cues and prompts used accommodations need to be carefully considered. In this case, support should focus on providing cues in such a way that the person may be able to do the task independently in the future. When spoken instructions are used to a person, the immediate results are often positive the person does what said. However, the spoken words may inadvertently become part of the task and a person may continue to need a supporter to say, “Put on your sock,” long after the sequence learned. Speaking involves relationship. If the task not one of relationship, speaking during the task about how to do it should be kept to a minimum. (For more information on the effective use of cues and prompts, see Donnellan, LaVigna, Negri-Shoultz, & Fassbender, 1988.)

Use of Scent Accommodations using smell can also be very effective for some individuals. The scent of coffee can get many of moving in the morning. Certain scents can relax some individuals and help them regulate their actions. Other scents, such food cooking, can bring a person to the kitchen. Some people have reported using a form of classical conditioning, where a scent becomes associated with relaxation and self-control and used to elicit those feelings during times many people have negative reactions and profound sensitivity to scents, caution should be exercised in exploring scent an accommodation.

Defining the Task When an individual has difficulty maintaining an action or attending to a task, it often helps to choose tasks with clear beginnings and endings, such stacking chairs, making popcorn, emptying waste baskets, and washing very dirty dishes. Even if the task does not have a clear beginning or end, you can create them by using time markers, such a bell ring. It also helpful to make the transformation or result of an activity more salient or obvious. Using color an excellent way to achieve this. You can use opaque foams and colored cleansers for scrubbing. Colored paper to end a stack can work as well. Teaching a motor pattern "rule" can help some individuals with both initiating and maintaining an action. Examples of this would be cleaning from one corner to another, washing each plate in a specific motion, and taking everything from the counter top and putting it on the table.

Accommodations for Perceptual Differences Each person has a unique and individual sensory system. An accommodation for one person may be a trigger for another. It is important to have knowledge of the individual and understand how their perceptual differences may challenge them. It may be helpful to work with sensory integration specialists, occupational therapists, physical therapists, or other professionals for specific guidance.

Environmental accommodations may help some people by fine-tuning the aspects of an environment that promote a person’s optimum participation and reduce stress. The accommodations below are a sampling, useful for some people in some situations.

Materials Many materials may assist in sensory integration and body comfort, thereby reducing stress levels for some individuals. The following materials have been successfully used as accommodations: tumble form chairs, bean bag chairs, chewy and crunchy things, tube necklaces, "feel good box," black light, weighted vest, foot or hand vibrators, light box, tinted glasses, earplugs or earphones, and heavy, padded clothing.

Reduce Sound Some individuals are sensitive to a variety of sounds. Pay special attention to background noise and sudden noises. Notice how competing noise, white noise, and loud noises affect a person's ability to pay attention. Remember that sometimes the senses mix. For example, for some people a loud noise may affect their ability to see things clearly or to remain standing. A way to reduce auditory reverberation might be to use carpet, cork flooring, ceiling tiles, and or large padded furniture. It is vitally important to have quiet spaces to get away from the stimulation of daily activity.

Reduce Clutter and Distractions Visual perception can also be challenging for many individuals. Reduce visual clutter while keeping materials visible and accessible. Reduce glare and visual refraction by turning off unnecessary lighting, especially fluorescent lighting; using matte finishes on surfaces and walls; using lamps instead of overhead lights; choosing low wattage light bulbs; and using soft colored light that cuts down contrast and color contrast in a room. Choice of colors for walls, floors, and furniture are important. Solid colors for the walls sometimes help people with depth perception differences to judge distances. One plain wall in a room can provide a visually 'quiet' space. Floors and walls should not be the same color. Some people report being able to move better when the floor pattern is compelling, such as floor tiles in a black and white pattern. An example of this is presented in the film Awakenings, where a patient is able to cross the room once the black and white pattern has been continued (Sacks, 1990). In the bathroom, a floor that contrasts in color to the toilet and other fixtures is helpful to some. Too much sameness among colors of walls, floors, furniture, and fixtures may make it difficult to see them as separate. The
furniture might be positioned around the periphery of the room in order to move around the room more freely or "navigate" without barriers or obstacles.

Understanding Touch Individuals have reported many accommodations concerning touch. Some people have difficulty with being touched and have learned to accommodate by avoiding the touch of others. Touch may be easier for some to tolerate if it is firm touch rather than light touch and is predictable or rhythmical. Grandin (Grandin, 1995; Grandin & Scariano, 1986) created a "squeeze machine" that provided firm pressure to her body that helped relieve intense anxiety and stress. Some individuals report that hugs and massage help provide comfort and kinesthetic feedback, while for others, such intense touch can be very uncomfortable or cause agitation.

Experimenting with Different Modalities Combining input from different sensory channels may be difficult for some people. Try stressing one modality at a time. For example, use fewer gestures when speaking, use touch sparingly, and signal your intention to touch before doing so. It is also important to not expect eye contact while a person listens. Consider that movement of others in the area may compete for attention. Experiment to find the right combinations for accommodating to a person's perceptual differences.

Accommodations for Speaking and Interactions

When interactions and speaking are difficult for a person, interpersonal accommodations that explore ways to develop and sustain a relationship are important. Interpersonal accommodations are aspects of support that focus on accommodating a person's differences within the relationship. When people do not use words to communicate and have difficulty using their bodies to express meaning, others sometimes assume the person does not understand what is being said. People who do not have a full range of facial expressions or cannot use their bodies or voices to express emotions are sometimes thought to not have feelings. People have told us that this is one of the most devastating aspects of learning, sensory, and movement differences. Speak to people directly. Although a person's disability may affect various aspects of interaction, it is most helpful to speak to people in a way that acknowledges their competencies. If comprehension appears to be a problem, use augmentation to add meaning to your words; explain yourself in several different ways or illustrate your meaning in some other way, through pictures with words modeling the activity. People must feel that they are part of the communication world in order to find the motivation needed to participate. Provide people with information, friendship, humor, and intellectual stimulation. Do not be afraid to ask an individual about the best way to support him or her.

A partner in an interaction with a person who senses and moves differently may consider accommodating or adapting communication in ways that may not be obvious to most people. Small changes may have a large impact on a person's ability to participate. During an interaction, remember that the melody of your voice may add or distract from your meaning. Try speaking with more or less intonation in your voice, using a soft melody to your voice, whispering, or speaking in a rhythm. A slower pace is often helpful for anyone when the person, place, or activities are unfamiliar. Pause after speaking (sometimes up to 20 seconds) and allow extra time for a person to respond (Miranda & Donnellan, 1986). Creating or maintaining a rhythm during the conversation may be helpful for some. If the individual is swaying or moving in a certain way, it may be helpful to match that movement or rhythm.

An interpersonal accommodation with great significance for many people is a partner who does not demand eye contact in order to continue an interaction. The lack of direct eye-to-eye gaze simplifies listening for some and produces a comfort that allows an easier flow of speech and other forms of expression. Some individuals need more personal space or distance between them and their partner, while others need to be in physical contact with a partner in order to stay with an interaction. For some individuals, physical contact can allow the emergence of speech.

Many people and their families report a benefit from an accommodation that combines touch, rhythm, communication, and emotional support to type or point to produce written language. This is sometimes called facilitated communicating. Support to the person's hand, wrist, arm, shoulder, or back helps some individuals communicate. This accommodation has been the center of research and media attention, much of it negative. Nonetheless, since the mid-1990s when the controversy was at its peak, some people who type to talk have worked hard to establish the validity and reliability of their words (Biklen & Cardinal, 1997). Some who began typing with physical support are now able to type without touch, but may need the presence of a trusted facilitator who provides other supports important for communicating (Broderick & Kasa-Hendrickson, 2001; Mukhopadhyay, 2000; Rubin et al. 2001). There are many resources available for those interested in knowing more about facilitated communicating (Biklen, 1993; Biklen & Cardinal, 1997; Brandl, 1999; Crossley, 1997; Donnellan, Sabin, & Majure, 1992).

Accommodations for Emotional Regulation and Expression

Each of us has specific ways to modulate our emotions and to reduce emotional overload, although we often use these accommodations unconsciously. We use emotional accommodations to regulate both positive and negative emotions as may be seen on television game shows where winning and losing contestants
struggle to "keep it together" with loud screaming, attempts to fight back tears, jumping up and down, wringing of hands, and repetitive speech, such as, "Oh my gosh, oh my gosh, oh my gosh!"

Some people with autism report that they work very hard to control emotions, both the initiation of the right emotion and the regulation of the intensity of the emotion. Many report "unfiltered emotions," or difficulty identifying which emotion one is feeling. They report that others often misunderstand their behaviors and their attempts to control emotions, partly because the context or source of an emotional stressor may not be evident or problematic to those around them. Imagine those game show contestants emoting strongly while standing in line at the grocery. Within the store context, the contestants would appear totally inappropriate.

The challenges with which people with autism struggle are often extreme. The most obvious emotional accommodation is to support and promote the confidence and self-esteem of people. Assuming and expressing confidence in a person can be a powerful support and should not be underestimated. Some individuals report that they can sense when a supporter is annoyed or frustrated. Humor can be used to distract a person from an anxious mood and make a situation seem less serious. The attitudes of supporters, whether or not these are specifically expressed, may affect an autistic person's performance, just as they affect the rest of us.

Some people report difficulty with knowing which emotion they are expressing. It may be helpful to let a person know when you see a fleeting sign of a positive emotion. Although a person may appear to be focused on other things and not show conventional signs and signals of relationship, they may be interested in and want relationships with other people. Let them (and others) know that you can see they are acting friendly, even if the signs and signals are unusual or fleeting.

It may be best to discuss difficulties of past behavior during calm and quiet times rather than bringing them up before or during an activity when there may be a problem. While briefing a person just before entering a challenging situation may serve as a reminder for some, for others, it may highlight the problems that they may encounter. In contrast, people report that when others express confidence in their abilities and highlight their competencies, they enter a situation with less anxiety. Some people report that when they are focused on self-control and a supporter brings up the topic of behavior to avoid, the person is more likely to have a problem. As with stuttering or other movement difficulties, naming a behavior to avoid sometimes causes that behavior to happen. Many people report that distraction from thinking about the behavior is more effective than direct reference to it. If one must talk about behavior in a situation, the focus should be on the positive behavior rather than the negative.

During difficult times, when a person needs assistance to maintain self-control, reduce the need to interpret the meaning of your words and use clear language with clear references. Keep conversational "banter" to a minimum, indicate topic switches clearly, and be clear in your intentions and message. Provide the person with more space, both physical space and spaces in the interaction. Having a space to self-regulate helps some individuals with emotional regulation and expression. Consider teaching a person to leave or avoid sources of provocation.

When a person is vulnerable or is having difficulty with emotional expression or regulation, try to monitor and limit the emotional load of the interaction. Individuals report a loss of sense of control at transition times or shifts from the expected. Some report feelings of performance anxiety with exposure of self and the experience of being the center of attention as too scary. Some report hyperexperienced sensations and emotions that can build when triggered by intense situations. The experience is too much feeling and may lead to destruction of one's own work, objects in the environment, attacking one's own body, or shutting down.

Emotions can build up, get mixed up, or become "stuck." "A little bit scared" can turn into terror, yet may be expressed by laughing. "A little bit upset" can turn into furious. "A little bit amused" can turn into manic, hysterical laughing. Direct confrontations may be raw, exposing, and emotionally provoking. When a person is vulnerable or losing control, a direct reference to the situation may be very unhelpful. Often, distraction and indirect references work better. Make a nonverbal offer, for example. Hold out your hand as an offer of support or gently push an object in the person's direction rather than ask if they want it. Try using the third person when describing what needs to be done: "When a person feels confused, it sometimes helps to . . . and then suggest a course of action. Direct your comments to "another" person or speak to the materials in front of you. Use objects to illustrate or explain interactions.

CONCLUSION

In this chapter, we suggest that the first-hand accounts of individuals with the problems associated with autism provide a rich source of evidence for the presence of sensory and movement differences and disturbances in the lives of these individuals. We have an emerging awareness that behaviors may not be what they seem. We need to rethink many of our previous assumptions regarding people's behaviors, paying attention to the insights of people labeled with autism, as well as published articles on sensory and movement differences. Some of the implications informing our thinking include (1) self-stimulatory behaviors may not be volitional or pleasurable; (2) automatic, habitual, impulsive, or overlearned responses may be difficult for a person to inhibit; (3) random bursts of activity, rapid fatigue, lethargy, or disturbances of a person's overall behavior may signal acute difficulties in sensory sensation and movement;
or not responding may be related to sensory integration and movement difficulties. These difficulties often are not evident to us because we are constrained by our neurotypical experience and social judgments and by the communication difficulties inherent in autism. Additionally, we suggest that the difficulties these labeled people have regulating and organizing thought, sensory, perceptual, motor, and emotional experience may cause, and even be exacerbated by, stress. It is not our intention to develop yet another set of characteristics to add to the plethora of diagnostic checklists available in our field. Rather, we hope to connect the experience of individuals with autism to the wide range of information about sensory and movement differences found in the literature beyond the field of autism.

We offer the notion of accommodations which was introduced and brilliantly presented by Luria (1932/1976) and by Sacks (1990) as a model of support. Personalized accommodations can be added to the other positive supports recommended for individuals with the labels of autism and other developmental differences. Personalized accommodations are also consistent with the principles of Person-Centered Planning, as discussed and practiced by many of our colleagues (e.g., Cattermole & Blunden, 2002; Falvey, Forest, Pearpoint, & Rosenberg, 1997; O'Brien & O'Brien, 1998; Snow, 1994). Our experience and that of our many colleagues who espouse such a personal and practical approach has the added benefit of expanding our own sense of empathy for those who have an often stressful experience navigating the ordinary events of life. To borrow from the words of the great physician and philosopher, Maimonides, once we can begin to understand their experience, we can never again see in these people anything but ourselves.

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References


Stress and Coping in Autism


D. Cohen & A. Donnellan (Eds.), Handbook of autism and pervasive developmental disorders (pp. 710-717). New York: Wiley.


