

Invited Commentary

Invented Knowledge and Autism: Highlighting Our Strengths and Expanding the Conversation

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Whenever the ratio of what is known to what needs to be known approaches zero, we tend to invent knowledge and assume that we understand more than we actually do. We seem unable to acknowledge that we simply don't know. (Rosenhan, 1984) (p. 139)

It is a pleasure to comment on this special *JASH* issue and to offer thoughts about current and future directions. It is like revisiting my entire career. The approaches are familiar, often interesting and exciting, yet perhaps more limited than this complex topic requires. As researchers and practitioners, we may have fallen into the conceptual trap that Rosenhan (1984) called "invented knowledge." Invented knowledge is not about deception but about self-delusion. It is about putting faith and reliance on what we think we know in order to ease the burden of working in complex human situations with less understanding than is comfortable. The term comes from a landmark study in which mental hospital personnel diagnosed researchers as mentally ill. Once they were inpatients, the ordinary behavior of these researchers was recorded and pathologized. Eventually, they were released with labels such as "schizophrenia in remission." Surrounded by a patina of confidence based on professional objectivity, medical and scientific jargon and definitions, these mental health professionals could not distinguish sanity from insanity. I raise the question whether we in the field of autism may labor under a similar burden of invented knowledge such that, confident in our objectivity, we sometimes forget our limitations. I will suggest further that we would profit from an expansion of our conversation beyond the present data set and conceptual models of what we know and what we think we know.

I started out knowing everything. In the early 1970s,

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a naive new college graduate with a psychology degree emphasizing operant conditioning, I developed one of the first preschool programs for children labeled autistic in the English speaking world (Donnellan-Walsh, 1976). I received hands-on training in applied behavior analysis (ABA) and autism from one of the staff members of an early UCLA project (Lovaas, 1967). I have maintained an interest in early childhood issues and teaching technology. I still question what we know about people with autism and how their disability should be accommodated (Cohen & Donnellan, 1987; Donnellan & Leary, 1995; Donnellan, Miranda, Mesaros, & Fassbender, 1984).

The lesson from my experience is great humility. Too many of the individuals I knew personally are now young adults who spent their entire lives getting over their autism (Lapin & Leigh, 1998). They are still living what Thoreau might have called "lives of not so quiet desperation," surrounded by people paid to be with them. Their behavior was modified in their early years by some of us who are still arguing about the most effective treatment for young children with autism. Their parents are still desperate (Donnellan, 1999). Desperate, too, are the hundreds of younger parents I meet, although they are more likely to believe that cure or recovery is at hand. I wonder what vision they have for their children's adulthood when/if the cure or recovery does not happen. After almost 60 years of studying individuals with autism, we have no cure, no clear definition of autism, we do not know what causes it, and we do not know which intervention is best for any given child (Bristol et al., 1996). I suggest that autism is not something that someone has, but a label for what we observe and experience. It is a partial and inadequate expression of the labeled individual's unique experience. What needs to be studied and known is the individual. I know far less today than I thought I knew when I began. Humility comes easy these days.

Throughout my career, behaviorism was considered by most the preferred scientific approach. Anderson and Romanczyk (1999) explicate that position very well. They present the model, clarify nuances that contribute to present controversies, highlight the consider-

able historical contribution of ABA, and note their own successful interventions. L. K. Koegel, Koegel, Harrower, and Carter (1999) and L. K. Koegel, Koegel, Shoshan, and McNeerney (1999) offer their original approach to pivotal behaviors, focusing on self-initiation, self-management, motivation, and responses to multiple cues. Likewise, McGee, Morrier, and Daly (1999) describe a program that teaches children with and without autism in an inclusive preschool. Their attention to detail in supporting interactions with typically developing peers focuses on child initiations and "... careful planning of the interface between environment and procedures that the teacher will use to dispense preferred materials" is impressive.

These papers continue the dominant historical approach to autism. As Anderson and Romanczyk note, there are about 500 ABA/autism studies. This is an important part of our history, although it does not necessarily reflect the consistent march of scientific progress, hope, and understanding of this human condition that several of these papers suggests. The present collection reflects more recent and welcome changes as they emphasize ongoing review of child change in more natural social settings and interactions. Earlier, interventions were occasionally remarkable, at times reprehensible, but often geared to demonstrating a procedural nuance rather than clinical value for an individual (Evans & Meyer, 1985; Guess, 1990). When we reflect on what we think we know, it helps to acknowledge that we built a science in autism on research that, following Uri Bronfenbrenner (1979), too often looked like strangers doing strange things with strangely behaving children (and adults) in strange settings for the briefest possible period of time.

Greenspan and Wieder (1999) extend the autism issues beyond the traditional behavioral model. Their functional/developmental approach and case histories situate a child in a particular nervous system within a particular family and school/social situation. Within such contexts, they are willing to consider the child's "intention" which they, and I, see as essential when dealing with a child with severe sensory processing, motor, and other well documented problems (Donnellan & Leary, 1995; Leary & Hill, 1996).

The behavioral papers stop short of considering this intentionality, although several of the papers discuss "motivation." L. K. Koegel, Koegel, Harrower, et al. (1999) carefully limit their discussion of motivation to "... observable characteristics of a child's responding, such that an improvement in motivation is broadly defined as an increase in responsiveness to social and environmental stimuli." Motivation is treated as a pivotal behavior and is targeted by varying child choice, tasks, and prompts. It is encouraging to see these useful strategies, although the limited definition does not address sufficiently one of the most complex topics in human learning (for a discussion of motivation and problems

of will, see Damasio, 1994; Luria, 1932, 1979). The careful way L. K. Koegel, Koegel, Harrower, et al. (1999) couch their brief discussion suggests that the authors know this.

Their caution may reflect an essential conundrum in the behavioral model when it addresses motivation, intention, or any private event. Anderson and Romanczyk (1999) present the topic in a way familiar to all of us who have been trained in the model. "The sine qua non of the applied behavior analytic approach is that objective measures are taken of the individual's behavior and that these measures must meet the boundary conditions of being operationally defined, reliable, and valid." They elaborate on their description of motivation and autism:

It is also the case that some individuals, such as children with autism, have impairment in motivation. At times, motivation may be quite idiosyncratic and limited in its extensiveness. An example would be children who are not motivated by social attention and praise, physical contact, and the sense of accomplishment for completing a task or solving a problem. Rather these individuals might find their own repetitive and stereotyped behavior more interesting and enjoyable, and thus engage in it disproportionately compared to prosocial behaviors.

Descriptions such as this are common in autism. They are part of the invented knowledge, perhaps inevitable in an applied field where there is so much to be done compared to what is known. We make tentative proposals and use shorthand descriptions based on broad assumptions and abstract labels for real and complex phenomena that are barely understood. Inventions are necessary to move forward. The problem arises when these become conventional wisdom, no longer questioned or challenged. We begin to believe more than we actually know so that even strict behaviorists may assume that they can know whether a child has an "impairment in motivation" or a "sense of accomplishment," or finds stereotypical behavior "more enjoyable" by observing the child's external behavior.

There is a shared belief that we can define autism, and therefore the experience of autism, from an "etic" or outsider's perspective (Schwandt, 1996a, 1996b). Certainly we have reliable information that individuals with autism prefer their own pursuits to social interactions (American Psychiatric Association, 1994; Cohen & Volkmar, 1997). Several of the authors acknowledge that our observational ability is based on our professional and social cultural bias, but assume that these can be overcome by our science (see Cole, 1996, for an excellent review of social/cultural effects on knowing). Validating our assessment should be a constant challenge; so should validating our assumptions and per-

ceived wisdom. We know what children with autism do but we do not know what they prefer to do unless we limit the definition of motivation to that which amounts to little more than an increase in responding in the presence of certain stimuli which we manipulate. Again, Koegel, Koegel, Harrower, et al. (1999) offer a potentially important contribution to our technology. However, if we were to use their work to assume that the motivation or preferences of typically developing people could be adequately assessed by the external interpretation of observers, we would be defying our own everyday experience. Yet, our shared belief, our invented knowledge, permits us to move incautiously toward such an assumption in the case of children and adults whose differences and challenges ought, instead, call out for caution.

Greenspan and Wieder (1999) are more willing to take on private events such as intention during assessment. They are also willing to acknowledge that the observable behavior of these children can be affected by functional limitations in critical areas, including language, motor planning and sequencing, sensory process, and modulation. They present assessment as a complex nonlinear task that must include biological and social/historical variables. They stop short, however, of a clear acknowledgement of our limitations. They never say, for example, that what we are observing at any given moment might not be what a child is actually choosing to do. Each article in this special issue implies that a professional gaze can adequately assess what a child intends. In the article by Greenspan and Wieder, the invented knowledge about the emic (insider's) perspective (Schwandt, 1996a, 1996b) is rooted less in behavioral precision than in a stance of advanced professional knowledge of child development and biology.

These articles reflect an ongoing and widespread belief in autism: that we can collect assessment data about children's deficits, pathologies, skill, and regulatory profiles relative to normal development or rating scales and, through this process, know them and their experience. Moreover, we believe that we can develop subtypes of such children based on this kind of information (Greenspan & Wieder, 1999; L. K. Koegel, Koegel, Shoshan, et al., 1999), even though Anderson and Romanczyk caution that there are "... as many differences between young children with autism as similarities among them." Although these approaches to assessment and grouping may be incrementally useful, they are risky if they contribute to our invented knowledge base, become part of our preconceptions of conventional wisdom, and, as such, are no longer challenged. We need to remind ourselves continually, clearly, and publicly that we cannot erase human variation by improving our reliability rates on diagnostic categories and subtypes nor wish away human complexity with reductionist observation models and behavioral definitions. I offer the following points to consider:

1. The possibility of complex and idiosyncratic movement differences that might confound our assessment and knowledge of an individual.
2. The need to include firsthand accounts in our story of autism.
3. Modern advances in biodynamic systems models of development and behavior, which can inform our knowledge base and practice.

Reports in the literature suggest that individuals with autism may be affected by movement differences and disturbances, which can render their performance, stereotypies, and behavior at any moment beyond their control or intent. Donnellan and Leary (1995), Leary and Hill (1996), and Rogers (1992) describe these differences in detail. Some well recognized movement disorders include Tourette's syndrome and Parkinson's disorder. Few today would assume that the motivation or intention of individuals so labeled could be validly discerned from their observable behavior alone, which often includes unusual and problematic speech, action, and emotional outbursts (Comings & Comings, 1991; McGoon, 1990; Sacks, 1989, 1990). In *Awakenings*, Sacks (1990) describes postencephalitic Parkinson's patients and reminds us that although they all had the same kind of brain lesions, they each created their own unique form of the disorder.

Behavior, which in the typically developing population would be called a movement disorder or a neurologic symptom (defined here as not necessarily under the individual's volitional control), is likely to be called a behavior disturbance (i.e., purposeful or functional) or self-stimulating (i.e., preferred) behavior in people with developmental disabilities or who were mentally ill (Rogers, 1992). In fact, the symptoms of autism fit remarkably well into the movement difference/disturbance category, which was first delineated and called catatonia more than a century ago (Kahlbaum, 1874/1973).

Some argue that there are no movement (often called motor) problems in autism (Mulick, Jacobsen, & Kobe, 1993; Rimland, 1993). In the Leary and Hill (1996) review of the autism literature, 155 papers described the presence of such differences in sensory, motor, speech, and emotional processes. Maurer and Demasio (1982) specifically noted the similarity to Parkinson symptoms. They were ignored, perhaps because their findings did not fit into the conventional understanding of autism as a problem of the mind. Such differences have been given little focus. However, Greenspan and Wieder (1999) have covered this issue in their article. More typically, the symptoms have been used to both define and explain autism with very little attention to what these symptoms might indicate about the experience of the person with autism (Donnellan & Leary, 1995). Consider the words of Temple Grandin, an adult with autism:

As a child I wanted to feel the comfort of being held. I craved tender touching. At the same time I withdrew from touch. Being hugged was like being swallowed by a tidal wave. . . . I was intensely preoccupied with the movement of the spinning coin or lid and I saw nothing and heard nothing. I did it because it shut out sound that hurt my ears. No sound intruded on my fixation. It was like being deaf. Even a sudden noise didn't startle me out of my world (British Film Institute, 1992).

What would our etic view (Schwandt, 1996a, 1996b) tell us of the preferences and accommodations of the young Temple? Would we say she had auditory or visual or tactile difficulties in her regulatory profile? Might we conclude she was not motivated to engage in social interaction?

Strandt-Conroy (1999) reviewed the literature on written reports by clinicians and parents and other adults with autism, and interviewed adults with autism who had verbal skills. Problems in starting, stopping, executing, combining, switching related to action, sensory-perception, motor, communication, thought, and memory were commonplace (Donnellan & Leary, 1995), but were poorly accommodated by those who were meant to support these individuals. Researchers have been building an empirical base that suggests we have misunderstood, and misreported, the presence and implications of sensory and motor difficulties in the life experience of individuals with autism (Blakeslee, 1999; Ghaziuddin & Butler, 1998).

One possible area of misunderstanding concerns our unchallenged belief that most individuals with autism are also mentally retarded. Young (1998) reviewed the seminal research on the topic (e.g., Rutter, Greenfield, & Lockyer, 1967) and found routine comments on the movement problems of the subjects, such as hypoactivity and hyperactivity and difficulty initiating movement. Yet, time based criteria were used without reference to or accommodation of possible timing and performance difficulties. Today, the canon in autism, the invented knowledge, is that we can validly test people with standardized instruments since nothing significant interferes with their ability to respond except their retarded development (Jacobson, Mulick & Schwartz, 1995).

From the point of view of infant research, Zelazo (1997a, 1997b) is particularly instructive about this presumed relationship between production and ability. He used the standard-transformation-return (STR) paradigm (Zelazo, Kearslye, & Stack, 1995), which measures clusters of visual fixation, cardiac changes, smiling, and vocalizing to test his hypothesis that performance difficulties might mask intact mental ability. He found that 75% of the 2 and 3-year-olds he studied, who had been diagnosed by other agencies as autistic and retarded, had typically developing processing. He then put these children into a developmentally based train-

ing program in which he taught parents to use shaping and other procedures. He found that 61% of these children misdiagnosed as retarded could "catch up" both in terms of school functioning and on standardized tests on 18-month follow-up. Moreover, Zelazo found that the optimal time for one-to-one sessions with the children was 12 minutes per day for at least 5 out of 7 days for 10 months. Today, there is a growing belief that "intensive" intervention by professionals of 30 to 40 hours a week is required for the reported positive results (McGee et al., 1999; Anderson & Romanczyk, 1999). Zelazo's data highlight the intensity issues raised by Greene (1996) and Anderson & Romanczyk (1999) and perhaps should cause us to scrutinize our work for inadvertent selection bias. Zelazo's report also challenges us to broaden our database to include more biological and physiological measures in addition to other observable behavior.

We do not know if Zelazo's approach is more valid than others presented here. However, it is a cautionary tale to avoid claims that any research or any intervention approach is privileged over others, however large its database or long its history. We need more detailed data, including more case histories, to begin to account for what actually is making a difference for any given individual. Vygotskian research models could be useful as they assume that such data can be collected on the process of child change (Cole, 1996). We need more first person accounts.

Greenspan and Wieder (1999) acknowledge the value of sensory-movement differences, the value of speech and language, sensory integration, and other interventions. However, they do not explain clearly the cross modal and unpredictable nature of the regulatory process and other problems an individual might experience such as those described by Temple Grandin (1995) and by Strandt-Conroy's (1999) subjects. Donna Williams (1995b) refers to these as sudden "system shifts and shutdowns." Such shifts can cause a person to be unable to move or to speak or may contribute to behavior that is very confusing to the individual and the observer. Moreover, she stresses the inconsistent, idiosyncratic, and unpredictable nature of the daily experience:

. . . system shifts and shutdowns which may be caused on one day by the excessive effect of shine, refracted light, florescent lighting, on another day by the allergic effect of perfume or the variation of a speaker's regular intonation. . . . lack of symmetry in the placement of things. . . . a sense of fullness in the bladder that hasn't been processed. . . .

She has written several books that are useful for teachers, parents, and researchers interested in autism (Williams, 1992, 1994, 1995a, 1995c). Her description of movement differences is entirely consistent with

Strandt-Conroy's (1999) research into first person accounts.

Whether or not the idea of movement disturbances ultimately is found to be generalizable to and useful for all people with autism, there is substantial data to make us cautious about our inferences about motivation or meaning of behavior based solely on the observable behavior of these individuals. As Leary and Hill (1996) explain:

Movement disturbance can clearly have a profound effect on a person's ability to regulate movement in order to effectively communicate, relate, and participate with others. Once this possibility is acknowledged, it becomes necessary to suspend absolute trust in one's intuitive interpretation of actions and intent. Behaviors may not be what they seem (p. 44).

There is much work to be done to understand these mind/body challenges (Sacks, 1989). Individuals with the communication problems associated with autism present particularly great challenges. It is clear that the stated experience of individuals with autism must be taken into account. Perhaps this is even the larger point. Anderson and Romanczyk (1999) argue that case studies and anecdotal reports are not acceptable substitutes for the empirical research approach they espouse. It need not be a question of "either-or." It seems reasonable that those of us who claim an objective gaze be at least obligated to consider the widest possible database for defining the phenomenon under study. As Nobel Laureate Gerald Edelman (1992) has suggested: "Objectivity is not absolute but depends on looking at a situation from as many viewpoints as possible" (p. 250).

Anderson and Romanczyk note: autism is a "... serious developmental disability that provides a complex challenge for parents, professionals, and all those who come in contact with the child." I would add that individuals labeled autistic face complex challenges and their perspective deserves mention when available. In particular, it would be instructive to hear from those individuals described as "recovered" or "indistinguishable" (Lovaas, 1987; Maurice, 1993; McEachin, Smith, & Lovaas, 1993) who are old enough now to speak for themselves. Although the researchers must respect confidentiality, the individuals themselves are under no such constraints. Individuals with autism and their families have shown remarkable generosity in sharing their experience in order to help others (see Strandt-Conroy, 1999, for a review). Of course, we may not like all that we hear. Strandt-Conroy found that few of her informants, all of whom are successful enough to live independently, valued the behavior change interventions they experienced. Perhaps because we seldom publish negative findings (Davis, 1998), we have developed invented knowledge around our interventions

that assumes that if the target behavior improves for an individual, then all other aspects of functioning are either unchanged or improved. We ought not to presume that everything we do is helpful, neutral, or harmless even in our most successful programs. It is time to invite these successful graduates of our various intervention programs into the appropriate public forum to offer their perspective on our work.

The traditional autism database, while large, simply does not exhaust the universe of evidence and wealth of research on the human condition that can be applied to the challenges of autism. The child development literature is likewise limited and is also being challenged by newer approaches outside the traditional canon. The biodynamic systems models that attempt to explain child development through chaos theory (Gleick, 1988; Guess & Sailor, 1993; Thelen, 1995; Thelen & Lockman, 1993; Thelen & Smith, 1996) argue that there is no "typical" developmental process. They provide compelling data on the truly unique nature of each individual's course of development. As Thelen and Smith explain, biodynamic systems are self-organizing, seeking preferred behavior modes as a function of the interactions of the components (e.g., thought, emotion, action, perception, memory, communication, posture) in a particular context. Through this interaction, behavior and development appear to emerge: "Although behavior and development appear structured, there are no structures. Although behavior and development appear rule-driven, there are no rules. There is complexity" (p. xix).

Two critical aspects of the chaos model, "sensitive dependence on initial conditions" and the "butterfly effect" (which holds that small changes can have large effects), may be particularly useful for understanding the unusual development seen in people with autism and the idiosyncratic nature of their experience (Grandin, 1995; Strandt-Conroy, 1999; Williams, 1992, 1994). At a minimum, the biodynamic systems research challenges our ideas of typical development and the notion of intensity in intervention. It also offers alternatives to the linear ways of thinking about research and intervention. With attention to the self-organizing and dynamic nature of human behavior and development, we may find that our invented knowledge base is larger than we imagined and that our interventions can be made more efficient and effective.

Summary

Each of the models discussed in this article and volume has a good research and clinical base and contributes to our limited knowledge. I suggest that the study of context would pull together these approaches in a very useful fashion. As Bateson (1972) told us, context is not just what is left over when we take out the part we want to study. Context is every part of the experience of the individual as well as the cultural/social history in

which learning is taking place (Cole, 1996). Chaos and biodynamic systems models provide a greater understanding of the critical nature of context. Chaos theory makes clear that everything counts in context and biodynamic systems suggests that knowledge is fluid; knowledge only exists in context (Edelman, 1992, Thelen & Smith, 1994). Greenspan and Wieder (1999) suggest a wide range of variables that may contribute to context and ways to accommodate them. The self-reports make a similar contribution, especially those that include comments on movement differences and individual's own accommodations, which may be difficult to observe from the "outside." The behavioral model provides a wealth of tools and experience for enhancing the environment (McGee et al., 1999) and clarifying and manipulating contextual contingencies (Anderson & Romanczyk, 1999; L. K. Koegel, Koegel, Harrower et al., 1999; L. K. Koegel, Koegel, Shoshan et al., 1999). Each should be included in our conversation about the development of young children with autism. Through such an inclusive conversation, perhaps we will know more. At least we will be clearer about how little we presently know.

As I write these words, I am aware of the recent passing of Arthur Schawlow, Sr. (Browne, 1999). Professor Schawlow won a Nobel Prize for his work on the laser and was one of the most honored scientists in the world. He was also a friend and advocate, and the parent of an adult son with autism, Arthur, Jr., who has lived through many behavior change programs that were considered state-of-the-art when he was a young child. These programs often exacerbated his problems (Schawlow & Schawlow, 1985). One of the many gifts that friendship with Professor Schawlow brought to me was a story of his early work in applied physics. He and his mentors and colleagues would have three lists on the chalkboard: (1) What we know; (2) what we need to know; and (3) what we are learning. Each time they added something to list three, they found they had to take something away from the first list and add to the second because new information inevitably revealed how little was actually known and how little they would ever know for certain. Professor Schawlow kept that list going throughout an extraordinary career and, he said, it kept him humble. In autism, we are studying a complex human condition and the human brain is the most complex object in the known universe (Edelman, 1992). Art Schawlow, Jr., others labeled autistic, and we as researchers, teachers, and advocates deserve no less than that to approach our task with hope, as these papers suggest, but also with a full measure of awe and humility.

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