

STRAIGHT TALK About *Autism*

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“To Advance the Mind We Must First Energize the Spirit”

A new year brings new beginnings and new resolve. Hearts and minds are more open to considering new possibilities and taking on new challenges. What better time to consider the challenge of how to “energize the spirit” of individuals with ASD. But first, I will share a story about why this is a worthwhile endeavor.

In 2005, I was invited to present a keynote workshop in Christchurch, New Zealand, for the Ministry of Education’s Early Intervention Conference. I was told that it was customary for the local Maori Iwi (tribe or clan of the indigenous people of New Zealand) to be invited to open the conference with a prayer service.

As I entered the packed room, I was directed to the podium and introduced to the Maori Elder. He was a tall gentleman, broad in stature, grasping a carved wooden staff that was as tall as he was. He was accompanied by 10 men and women from his Iwi who formed a line facing the audience. He approached me warmly to explain that the opening ceremony would involve the Hongi, a traditional greeting that involves each person pressing his or her nose and forehead against the nose and forehead of the other person two times, holding the contact slightly longer the second time. It is a Maori greeting that symbolizes “sharing of the spirit.” He informed me that as part of the ceremony, I should proceed down the line of members of the Iwi, but that if I did not feel comfortable with the Hongi, I could simply shake hands. I chose to do the Hongi out of respect for their tradition.

As I stood up preparing to be introduced, the Elder approached me, leaned over with his lips practically touching my right ear and whispered, “I trust that you will convey the message that in order to advance the mind, we must first energize the spirit.” As I took in his words, I felt a vibration

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shoot through my body, and understood that what he did was very targeted and intentional. I knew instantly that his message was very special, and that I would never forget that moment or his words.

Opening Our Hearts and Minds to Energizing the Spirit

How does the Elder’s statement relate to children and people with autism? A recurring theme in my school consultative work concerns the inordinate focus that, too often, is placed on academics or learning pursuits of questionable relevance to a person’s life, such as learning to respond to questions, follow commands, and regurgitate information as a marker of progress. Educators, therapists, and parents express the concern that a disproportionate amount of time is spent on imparting information and teaching compliance, since these endeavors take a great deal of time and attention away from social, emotional, and communication development—the areas of greatest need for children with ASD. Two things are important to consider: 1) research has demonstrated that progress in these areas is most predictive of positive long-term outcomes; and 2) these areas are especially germane to a discussion of the human spirit. Hence, when I look at programs for students with ASD, I look for practices that support engagement with others; foster joy; promote a sense of self; and instill feelings of accomplishment—in other words, practices that energize the spirit.

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I acknowledge that in this age of data-based decision-making and evidence-based practice, some professionals may be uncomfortable with a discussion of the amorphous concept of *spirit*. Perhaps a definition that best fits the meaning conveyed by the Elder will help to alleviate concerns. Spirit, as discussed in this article, is the “animating force within living beings.” It is what motivates us to be active and exploratory, rather than passive and complacent; to engage and to risk, rather than retreat and avoid. In short, it is the invisible force that motivates us to seek out enjoyable and emotionally satisfying activities and experiences with others.

While spirit does not lend itself to easy definition, let's recognize that it is a concept we commonly refer to when describing individuals. For example, children who like to be in the middle of the action and who enthusiastically engage with others are often described as *high-spirited*. In my consulting, I often make comments such as, *He's got a great spirit; She's a spirited kid; or They're such free spirits*. In short, these are the types of individuals who draw people to them and can fill a room with joy.

In contrast, we all have met people with ASD whose experiences in life have been extremely challenging, resulting in high levels of anxiety and even depression. We've seen kids who are struggling, frequently emotionally dysregulated, and overwhelmed or confused. They may appear lethargic or passive; may disengage or shut down; and/or retreat and avoid interaction on a regular basis. Their range of emotional expression may be limited or constrained, and they rarely share positive emotion with others. We may comment, “His spirit has been broken,” or “How can we motivate her and lift her spirits?” But then over time—and with the right support—many of these individuals begin to communicate and engage more successfully, as well as cope with challenges that previously were overwhelming. In short, they seem better able to derive more pleasure out of life. Many parents have expressed excitement over the blossoming of their child's personality (i.e., spirit) and have noted that despite their child's challenges, his (or her) spirit keeps them going.

Below are several ideas for how to energize the spirit as a part of our educational and treatment efforts. Think of these as ways to treat the “whole child” rather than as isolated suggestions

separate and apart from educational programming or daily living activities.

How Can Parents and Professionals Energize the Spirit?

- 1. Identify and nurture abilities, interests, and motivations –**
In a previous column, I focused on the importance of identifying and building interests, strengths, and passions rather than overly-focusing on difficulties and challenges—to take a “cup half-full” rather than a “cup half-empty” perspective. This is not always easy to do, and may require that we suspend judgment, since what is motivating or interesting to a person with ASD may be of no interest to us. Further, we must take care not to impose our own interests onto individuals with ASD in order to make the person look “normal.” A good rule of thumb: If the interest creates enthusiasm and positive emotion, rivets attention, or motivates a child to engage in and even share interests, it will go a long way toward energizing the spirit.
- 2. Encourage initiation, choice, and active engagement –**
A lack of control and rigid external constraints result in passivity and have a negative impact on one's spirit. In contrast, when we make a well-regulated state a priority; provide many opportunities for choice-making and active engagement; build self-determination; and support communication, we provide the essential building blocks for energizing the spirit. Opportunities to express choice may range from a preschooler choosing a toy or activity, to a school-age student choosing an after-school club, to an adult choosing a hobby. A positive quality of life is predicated, in part, on one's ability to have desirable options from which to choose.
- 3. Provide opportunities for physical activity, expressive and creative arts, and play –**
Too often, we overly “program” the schedules and daily routines of people with autism. Yet, we often observe the expression of positive emotion and greater spirit in more natural circumstances, where there are greater opportunities for spontaneous exploration and fun. The types of activities that energize the spirit are those that enable creative expression, such as music, dance, and visual arts, as well as play with peers. Additionally, regular exercise and movement opportunities provide positive emotional experiences and the sensory input that supports physical health and well-being. An adult with autism once shared, “I have been trained to act normal and not autistic, so that I have to basically go out and put on an act.” What was striking to me and to others who know her, is that she expresses more joy and enthusiasm, and demonstrates a greater and more energized spirit when she is allowed to be “autistic.” It is at those times when her personality shines through. Indeed,

she also is most spirited when “trampolining” and ice-skating, two of her favorite activities.

4. Surround your child with people who demonstrate appreciation and respect – We can all relate to the energizing impact of being with people who like us, appreciate us, and respect us for who we are. Conversely, being with people who are highly judgmental, always correcting us, and who demonstrate little appreciation for who we are and what we enjoy has an oppressive impact on our energy levels as well as our self-esteem. I know a young man with autism who was employed in a bakery and loved the work. He soon came to dislike the work environment as staff was not supportive and respectful of each other. As a result, he secured a new job in another bakery, and found greater joy and comfort in the positive, productive, and “spirited” environment created by the owner, who encouraged staff to express appreciation and respect for each other.

5. Foster a sense of safety and security – It is virtually impossible to experience joy, pleasure, and happiness when a person needs to expend an inordinate amount of energy in a protective stance to cope with insecurities, confusion, and threatening circumstances. On the other hand, when people, environments, and activities foster a sense of trust, safety, and emotional well-being, one’s spirit is more open to being energized.

6. “Showcase” and “Show off” a person’s interests and abilities – A few years ago I had the opportunity to interview Temple Grandin on the topic of identifying and building interests, strengths, and talents. In response to my questions about if and how this had been done with her as a young child, she responded:

My art abilities were always encouraged. One time I made a drawing of a beach and my mother thought it was good enough to put in a frame and put on the wall with the grown-up pictures.

Getting that kind of recognition was good.


Over the years, I have observed that when the accomplishments of individuals with autism are recognized and celebrated, it not only has a positive effect upon their self-image and self-esteem, but also an energizing effect upon their spirit. Furthermore, this is true for all individuals, regardless of ability level.

A Final Thought

In the coming new year, as family members and professionals, we are provided with the opportunity to reflect, change, and set a new course for our students and loved ones with autism. May finding new and creative ways to energize the spirit be at the top of all of our “to do” lists. 🏠

Author’s Note: Sincere thanks to the many parents, professionals, and persons with autism who have provided their reactions to my question: *What do you believe we must do to energize the spirit of persons with autism?* Their input is interwoven throughout the article.

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Dr. Barry Prizant has more than 40 years experience as a clinical scholar, researcher and international consultant to children and adults with ASD and their families. He is an Adjunct Professor, Brown University, and Director of Childhood Communication Services, a private practice. Barry is co-author of *The SCERTS Model: A comprehensive educational approach for children with ASD* (Prizant, Wetherby, Rubin, Laurent & Rydell, 2006) and the assessment instruments, CSBS, and CSBS-DP (Wetherby & Prizant, 1993, 2002). He has published more than 100 articles and chapters and has presented more than 700 seminars and keynote addresses in the US and internationally. Barry developed and co-facilitates an annual weekend retreat for parents of children with ASD, and is the recipient of the 2005 Princeton University-Eden Foundation Career Award for “improving the quality of life for individuals with autism.” For further information, go to www.barryprizant.com, or contact Barry at Bprizant@gmail.com.

NewsBrief

Mind Institute Researcher Partners to Speed Development of Treatments for Autism

October 15, 2013 (Sacramento, Calif.) — Jacqueline Crawley, the Robert E. Chason Endowed Chair in Translational Research in the Department of Psychiatry and Behavioral Sciences, will participate in the Preclinical Autism Consortium for Therapeutics (PACT), a new partnership sponsored by Autism Speaks to facilitate the discovery of effective treatments for

individuals with ASD. Other collaborators in the initiative are Mustafa Sahin, Boston Children’s Hospital, and Richard Paylor, the Baylor College of Medicine in Houston.

The partnership will develop a platform of preclinical tests in rodent models of genetic risk for autism that will evaluate and compare new medications and assess their effectiveness for ameliorating abnormalities in

social interactions, communication, anxiety, cognitive, repetitive, sensory, attention, hyperactivity, and electrophysiological brain activity in people with autism. 🏠

The initiative is funded with a two-year, nearly \$800,000 grant to Crawley from Autism Speaks. Media Contact: Phyllis Brown, telephone: (916.734.9023) E-mail: (phyllis.brown@ucdmc.ucdavis.edu)