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## feature / *The Culture of Autism*

Message from our April *Autism Advocate* guest editors, Ruth Elaine Hane and Valerie Paradiz, Ph.D., co-chairs of the Panel of People on the Spectrum of Autism Advisors (PSA)

ARTWORK: "RAINBOW TREE" BY DONNA WILLIAMS



# Accepting and Valuing Difference

We are thrilled to introduce a series of articles that reveal the rich diversity of voices of individuals on the spectrum of autism. As you read this unique issue of the *Autism Advocate*, we also invite you to go beyond our voices and our styles of expression to imagine our contributors as a gathering of autisms—a plurality of neuro-biological differences that are expressed in the whole body, the whole person, not just the brain. Together, we share our stories and expertise, offering a glimpse into what we call “the culture of autism.” We do so with the hope that our greater community—families, professionals, researchers and educators—might discover new ways to integrate the information and perspectives we offer into their daily life and work, with the common purpose of building bridges of understanding across all segments of our autism community.

ference. The curious aspect to difference is that, at first encounter, we experience it as something uncomfortable. An immediate, almost visceral feeling of “us and them” arises, creating unnecessary division and sometimes causing fear. This occurs in mainstream culture every day, when we encounter differences of race, class and gender. Similarly, the “us and them” phenomenon arises where disability is concerned. It even occurs within our own autism community, in places that we might not see or have never thought to look. However, when human beings become friends and peers, we let go of the obstacles that divide us, consciously or not. In fact, we learn from and value our differences. They are gifts, urging us to expand in our humanity and, by extension, to become more flexible as a culture.

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**BY RUTH ELAINE HANE AND  
VALERIE PARADIZ, PH.D.**

In the following pages, you will read an array of insightful personal stories, well-researched analyses and expert reporting on a variety of crosscutting issues within the autism community. In some way or another, they all touch upon the important subject of dif-

## Establishing a National Presence

Over the past 15 years, people with autism have created a national network of individual initiatives and self-run organizations with the goal of raising awareness of our right to autonomy, independent decision-making and advocacy for change. Some of our earliest voices include Temple Grandin, Ph.D., spokesperson and author; and Jim Sinclair and Donna Williams (a featured artist in this issue), who founded Autism Network International and organized Autreat, annual self-run retreats for individuals on the spectrum that still take place today. Jerry Newport initiated the first adult peer support group for adults with autism, AUGUA, in Los Angeles. His story recently became the subject of a book and feature film called *Mozart and the Whale*. Today our fellow PSA member, Sharisa Joy Kochmeister, is the presiding President of the Autism National Committee (AUTCOM) and a contributor to this issue.

Indeed, for those of us with autism, a first encounter with others on the spectrum is frequently one of immediate familiarity, a sense of finding one's own people.

In many respects, our grassroots efforts have reached mainstream proportions; many of our spokespeople and strongest advocates have appeared on national radio, on television and in the print media as voices of direct experience that need to be heard.

And yet, there are many individuals with autism who have not had the opportunity to tap into this amazing cultural development that has become both a partner and a force in advocating for wide-ranging quality-of-life issues for which all of us in the autism community strive. We dedicate this issue of the *Advocate* to these peers, extending a hand of friendship and a warm salutation, "Welcome; come as you are!"

## Kindred Spirits

Indeed, for those of us with autism, a first encounter with others on the spectrum is frequently one of immediate familiarity, a sense of finding one's own people. Fourteen years ago, at one of the first conferences devoted to the subject of Asperger's syndrome, tears welled in our eyes as we listened to the keynote speaker, Donna Williams, author of *Nobody Nowhere*, urging us to "Be strong. Have courage. You can endure." After her speech some of us shared with each other that listening to Donna and meeting in groups felt like a homecoming. Likewise, those who attended retreats like Autreat for the first time and experienced the cultural immersion of being among kindred spirits shared moments of profound personal insight and self-discovery.

Such opportunities to be with one another and learn from our direct experiences in safe, open forums have enhanced our lives—from work, to sexuality, to education, to family life and community integration. Today there are many peer groups available to us for regular meetings and activities. We have found that those that are the most successful and have the greatest longevity are organized and led by individuals on the spectrum, such as the Aspie Get-Together

in Minneapolis, facilitated by Ruth Elaine Hane; the Autastics of the San Francisco Bay Area; and the national network of peer support meetings pioneered by Michael John Carley, Executive Director of the Global Regional Asperger Syndrome Partnership (GRASP).

## Building Bridges

Together, we continue to nurture "autistic culture" by spending time with one another professionally, privately and in public venues. We also continue to learn from our fellow stakeholders who play important roles in the autism community—our families, therapists and doctors, teachers and support people. We have achieved a great deal in an advocacy environment that is complex. On one hand, we continue to strive for a cultural expression and self-awareness that transcends traditional psychiatric, medical or therapeutic views of who we are. On the other hand, we wish to collaborate with neurotypical professionals and advocates to advance our quality of life across all sectors. Indeed, our efforts have gone through many stages, encountering numerous stumbling blocks along the way.

To this day, we continue to discuss among ourselves what our most important messages are as individuals with autism, and we debate with one another about the most effective ways for delivering them. In addition to our own negotiating processes with one another, we find ourselves in dialogue with the community that purports to "help" us, hoping, as self-advocates, to challenge some of their perceptions of us while striving together toward the greater good—building bridges as friends and collaborators.

## Panel of People on the Spectrum of Autism Advisors

### *A Valuable ASA Resource*

Over the years, as we met people on the spectrum of autism who attended ASA's National Conference and when we visited chapters in the various regions, we noted that we were missing a valuable resource of knowledge and professional experience. What we needed was a panel of thoughtful leaders on the autism spectrum who could address some of the perplexing problems in understanding and treating autism, much like ASA's long-standing Panel of Professional Advisors. Individuals on the spectrum were frequently presenting at conferences and trainings around the country on topics of interest to the Board and ASA members, and we wanted to bring some of these individuals together to focus on issues faced by our community every day.

In 2006 several Board members were appointed to form a committee to develop a plan for creating a Panel of People on the Spectrum of Autism (PSA), who could serve in an advisory capacity to the ASA Board of Directors. The committee members included Ruth Elaine Hane, Herm Fishbein, Stephen Shore and Jerry Silbert. In July 2007, ASA appointed five PSA members to represent the culture of autism and advise the Board in decisions regarding the autism community.

Members of the PSA play a role in ASA's National Conference, including visiting the conference site to identify potential sensory problems for attendees on the spectrum, holding a preconference workshop, offering an "Ask the PSA" session, and hosting an annual Town Hall meeting where participants on the spectrum can meet with one another and express their opinions on matters that concern them. In addition, members of the PSA fulfill speaking engagements, sit on panels, and review and provide feedback on ASA materials. The PSA is a critical component of the Autism Society of America and helps ASA achieve its mission to improve the lives of all affected by autism.

ASA would like to extend its gratitude to the current PSA members:

Valerie Paradiz, Ph.D. (Co-chairperson)

Ruth Elaine Hane (Co-chairperson)

Dena Gassner, MSW

Sharisa Joy Kochmeister

Lars Perner, Ph.D.

Sondra Williams