

STRAIGHT TALK

About *Autism*

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Reflecting on the Journey

A Retreat for Parents of Children with Autism

February, 2010 marks the 15th anniversary of our annual weekend retreat for parents of children with ASD.

Therefore, it is fitting that this issue's "Straight Talk" column focuses on this innovative family support activity that has become a highlight of the year for this article's authors, and for many of the approximately 60 parents of children with ASD who join us each year. Over the years, the parent retreat has taught us so much about the challenges and triumphs of raising a child with ASD, experienced by families of varied ethnic, cultural, and socioeconomic backgrounds. It also has enlightened us as to how a relatively straightforward event that occurs over a 30-hour period once a year, can have such a powerful impact on parents and caregivers, and ultimately on extended families and their children with ASD. More than anything else, the retreat has demonstrated the profoundly energizing impact of providing parents with an opportunity to step out of the craziness of everyday life, and connect with others who understand the experience of autism. In this context, parents are able to share their stories—joyful and humorous as well as frustrating and even agonizing—and know that they will be listened to by compassionate compatriots who share similar challenges in their lives' journeys. There also are many opportunities to take stock of the year—have fun and laugh and cry—while being fed well and cared for, rather than being the care provider.

The Initial Inspiration

Almost 20 years ago, two of the authors (BP and EM), while on vacation, began to reflect on the restorative benefits of having

the opportunity to "get away", enjoy nature, and break the stress cycle of life's everyday demands. In our careers, our work has involved supporting families who experience a multitude of practical as well as emotional challenges related to raising children with ASD and other developmental disabilities (BP), and with medical emergencies and chronic medical conditions (EM). We began to consider that such get-away opportunities were rarely, if ever, available to parents we worked with on a regular basis, and who experienced moderate and often chronic levels of stress in their daily lives. We knew that our ability to get away provided us with a number of benefits: the opportunity to distance ourselves from everyday routines and to reflect on the challenges that were embedded within these routines; the opportunity to reframe—that is, to develop a slightly different perspective on life's challenges; to nurture and strengthen our relationship; and ultimately, the opportunity to emotionally "refuel" to be better prepared to deal with the inevitable stressors that are part of the routines of everyday living. From these experiences, sprung the commitment to create similar opportunities for parents for whom such getaways could not only be helpful, but could also fulfill an essential unmet critical need. We intuitively knew that offering such a retreat experience, run primarily by professionals, would come up short. The retreat needed to be developed and facilitated through a partnership with parents who were highly sensitive to and trained in meeting the needs of other parents. We (BP and EM) discussed the idea with a long-time time friend and colleague (BD), and a partnership was created with Community Autism Resources, a parent-run family support agency. Thus, the "Reflecting on the Journey" retreat was born.

Why a Retreat?

The need for a retreat was supported by our practical experience with parents; our knowledge of supports that parents report as being most helpful; and our research on stressors impacting parents of children with ASD. Common stressors include a sense of isolation; challenges related to their child's behavior; the need to explain autism to others; embarrassment in public; fatigue due to sleep deprivation; the impact of autism on familial relationships; and feelings of "not doing enough", often resulting in chronic stress and uncertainty about the future. Helpful supports for parents include a good night of sleep; non-judgmental social support; opportunities to share experiences and establish relationships with other parents; and being able to let down, have fun, and not be "on" all the time. Moreover, the retreat setting provides a safe "we're all in this together" context. We did not realize at the beginning how much the retreat would provide an emotional "opening" for parents. This required a high degree of sensitivity and attention to providing caring support when strong emotions surfaced within the safe and compassionate environment. This often occurred to the surprise of the parents themselves, especially fathers.

The Design and Format of the Retreat

The retreat was designed to provide a relaxing and supportive environment for parents or other caregivers to reflect on, explore, and share the rewards and challenges of raising a child with ASD. Initially, we did not have high expectations. We thought that if we could provide a brief "breather" for parents that would be enough within a day and a half format. Hence, the retreat needed to provide opportunities for rest and relaxation; discussion; social support networking; making new friends; and learning from other parents. However, knowing that a great stressor on parents is the feeling of having little control over events in their lives, we always emphasize in the welcome session that all participants should feel free to do what they feel they need to do—attend sessions; take a walk with their partner; sleep in; read a good book; or whatever they feel would nurture and serve them best. We do, however, urge parents to attend the opening/welcome session where everyone is introduced; the philosophy and schedule of the retreat are reviewed; and parents are invited to share their intentions for

the weekend. We also emphasize the importance of the closing circle, when we reflect on the retreat experience. Some parents also use this opportunity to reflect on the past year and prepare for the coming year.

We knew that the setting would be important, so we chose a retreat center in a beautiful, tranquil country setting affiliated with the University of Rhode Island (*see page 27*). It has remained our "home" all these years. (A weekend at a downtown Holiday Inn just wouldn't cut it!!) We also knew that the format needed to be different from a conference or typical support group meeting run by professionals or family support agencies. The experience needed to be one of immersion; and the atmosphere needed to be relaxed, casual, and accepting. In other words, it needed to be devoid of the stressors inherent in raising a child with ASD, and free of the harsh judgments often rendered by strangers or even trusted friends and relatives. To support this "immersion" experience, we ask that parents commit to an overnight stay, and that they attend from the opening welcome on Saturday morning through the closing circle prior to Sunday lunch. By requiring a commitment for the full weekend, the retreat becomes an experience that has a natural flow and sequence, which engenders respect and trust in the process and among all participants.

The "Nuts and Bolts" of the Retreat

The retreat draws 50-60 parents each year and the agenda follows a specified format that has evolved over the years, including the full group opening welcome session and closing circle; three discussion/activity periods, each offering three to four concurrent 90 minute sessions of loosely structured, small discussions or activities (each with one or two facilitators). Topics for the discussion/activity sessions have developed into three

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strands: 1) issues related to the specific experiences and challenges of understanding and supporting the development of children with ASD (e.g., communication and emotional regulation, nutrition and diets, and identifying and building

strengths and talents); 2) issues related to personal experiences and coping / adapting (e.g., dealing with agencies and schools; public encounters; family routines; issues affecting siblings and extended family relationships); and 3) issues and activities related to the importance of self-care and self-nurturance (e.g., yoga, massage therapy, aromatherapy, scrap-booking, and outdoor team-building activities). One of the clearest trends that has evolved over the years is the ever-increasing involvement of “veteran” parents suggesting topics and facilitating discussions based on their experiences, expertise, and talents.



Clockwise from L-R: The beautiful lake setting provides the restorative benefits of “getting away”, enjoying nature, and breaking the stress cycle of life’s everyday demands; A gathering place for parents to relax and engage in quiet conversation; The retreat provides an opportunity to connect with others who understand the experience of autism. (Photos courtesy of Dr. Barry M. Prizant)



An essential nurturing aspect of the retreat is food and fun! The retreat includes five nutritious, delicious, and plentiful meals served buffet-style at family-style tables of six to eight persons. There are also fun activities including free time for recreation (hiking, hay rides, canoeing); a wine/cheese/cocktail hour; and Saturday night entertainment, that has ranged from bands and DJ’s, to movies, bonfires, and games – “like an adult summer camp!”, as many parents have commented.

Parents who have attended range from experienced parents with adolescent and young adult children, to those with recently diagnosed very young children. Mothers and fathers who are married or single attend, as do parents without their partners. Over the years, some parents have returned annually to the retreat, while others have attended for some but not all of the years. Some parents who attend alone for their first year come back with their partners in subsequent years, and each year we have a core group of “first-timers”. We estimate that we have directly touched the lives of approximately 400 parents in the 15 years of the retreat.

Initially, funds were provided through state seed grants, but for the majority of years, funds have been raised primarily from proceeds from our annual ASD conference. Due to the tough economy affecting conference attendance, the retreat has recently been supported, in part, by Bailey’s Team, a local philanthropic foundation. Eighty per cent of costs are

subsidized for most parents, and parents with significant financial limitations may attend cost-free. Attendees have come from six states, primarily from the Northeast. An interesting note: When we surveyed parents a number of years ago about their interest in our making arrangements for their children to attend, 80% indicated *no*, as they felt that it would be a very different experience, and that it would not serve the purpose for which the retreat was created.

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The Impact

Evaluation questionnaires and reflections voiced in the closing circle over the past 15 years suggest that the retreat has become far more than a weekend “breather” from the stress and challenges of raising a child with ASD. Parents report sustained long-lasting effects, and some describe a remarkable impact. Parents who have attended more than one retreat indicate that it provides them with an opportunity to regularly reflect on the challenges and successes of the previous year; strengthen their marriages and family relationships; and establish new relationships (that often continue) with other parents. In addition, it also enables not only the sharing of resources to cope with and address everyday challenges, but also encourages the development of new coping strategies so that they can return home with a renewed sense of energy and purpose. Sample feedback from parents includes the following themes:

- Some parents note that the retreat is the first time they were away overnight, including periods of up to 10 years since their child’s diagnosis. They learned they can be away overnight and everyone “will be OK”. In some cases, parents seek respite support from relatives or agencies for the first time.
- Many parents note that the retreat marks “our New Year”, with an opportunity to move forward with new energy and new ideas.
- Parents who have experienced significant marital issues have noted that the retreat “has saved our marriage”, as they are able to see that other families have similar stressors and challenges. Thus, they feel less isolated; are more motivated to seek support; and better understand how the experience of autism can affect marriages and family life.
- Returning parents report they “count the days” until the next retreat so that they can see old friends and refuel for the coming year.
- Almost all parents come away with new ideas and strategies; openly express their love for their child; and have the chance to reflect not only on the challenges, but also on how having a child with ASD has also had a positive impact on the life of the family.

When we discuss the retreat with professionals and parents around the country, we have learned that “Reflecting on the

Journey” is truly a unique and cost-effective model of support that has a broad-ranging impact on parents during and beyond the weekend. We are in the process of seeking funding to make an educational DVD describing the retreat, so that we may share this experience with those who have interest. We hope that this brief description of the retreat (notwithstanding that it is impossible to capture the depth of the retreat experience in words) motivates parents and professionals to create and seek out similar types of innovative family support activities. 

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Dr. Barry Prizant is the Director of Childhood Communication Services and an adjunct professor in the Center for the Study of Human Development, Brown University. Barry has more than 35 years of experience as a researcher and international consultant to children and adults with ASD. He has published more than 90 articles and chapters on childhood communication disorders and has given more than 500 seminars and workshops at national and international conferences. He also serves on the Editorial Boards of six scholarly journals. Barry is a co-author of the SCERTS Model (Prizant, Wetherby, Rubin, Laurent & Rydell, 2006—www.SCERTS.com). In 2005, Barry received the Princeton University-Eden Foundation Career Award “for improving the quality of life for individuals with autism”. For further information about Barry’s work, go to www.barryprizant.com, or contact Barry at Bprizant@aol.com.

Barbara Domingue, M.Ed. is the Executive Director of Community Autism Resources, Inc., a family support agency which provides a variety of resources to individuals with A.S.D., their families, and the professionals who assist them. She has been actively involved in the areas of family support and autism consultation for the past 22 years and has served on numerous state and national boards. Her involvement in the area of A.S.D. has evolved from her experiences with her 26 year old son with autism. She (along with her colleagues) has published a chapter on the topic of the experience of autism in the lives of families in the book *Autism Spectrum Disorders: A Developmental Transactional Perspective* (Wetherby and Prizant, 2000).



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