

STRAIGHT TALK About *Autism*

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Finding Balance

WHEN I WAS INVITED to present a keynote address at the Southern New England Autism Speaks Luncheon for the annual Fall Walk, I thought, “How can I present a talk that is both relevant to the event, and also provides some meaningful discussion about the crucial issues faced by parents, families, practitioners, researchers, and individuals with autism—the ultimate beneficiaries of such walks?”

Then it came to me: *Balance*. It’s the one necessary skill for participating successfully in a walk for autism, since to participate successfully one must be able to maintain appropriate posture and balance. Finding balance has also proven to be one of the great challenges faced by parents, families, practitioners, and researchers in autism, and indeed, individuals with autism. Let’s reflect on this theme as we explore the issue of finding balance. No quick answers or solutions here. Much of what I will be discussing comes from both research, as well as my 40 years of experience working with persons with autism and their families, which began as a teenager when I was a counselor in summer camps.

Families Finding Balance

Many aspects of the experience of having a child or family member with autism relates to the challenges of finding balance. Research on the major stressors on families indicates that social isolation, the feeling that few people understand, isolation from community events and everyday activities—and for some families—the growing isolation from family members and even friends and relatives, all lead to a feeling of asynchrony in life—a profound lack of balance. Finding balance in family life may be difficult, even regarding very basic issues in everyday life routines. Some examples: How do I find time for my child or children who do not have special needs? How much risk should we take by trying to go to places and do things that most other families do? Do we dare to try to take a vacation, which by its very nature is a break in routine, with new and different experiences, when our child so needs routine and predictability? How do I find time for my husband, wife, or partner? Probably one of the greatest challenges to balance experienced by family members is the feeling of a lack of control, and fear and uncertainty regarding the future.

Treatment and Education

Twenty to thirty years ago, it was not uncommon for parents to lament the fact that there was so little information for parents about autism, such as treatment options, support groups, trained professionals in the field, and so forth.

Today, the problem seems to be the reverse—there is an information explosion. Parents must try to maintain balance while navigating through the sea of treatments and the unlimited number of self-proclaimed experts, many of whom claim that he or she has THE RIGHT APPROACH or THE RIGHT ANSWERS to their child’s challenges. Of course, every parent wants to do the best for his or her child, but how does one assess the credibility of the “experts” who make such extravagant claims about the effectiveness of a particular treatment? Parents must wade through the options hoping to achieve some balance—a “program” that makes the most sense for their child without exhausting the emotional and fiscal resources of the family. Considering the broad landscape of treatment options, how much attention should be given to a child’s education compared to his or her biomedical and nutritional needs?

For children and adolescents in school programs, the question becomes how to balance academics versus self-help, and other functional skills versus social relationships and leisure skills. Should a child’s program shift to a

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greater emphasis on vocational and independent life skills, and if so, when should this happen? What is the appropriate balance?

How much should professional educators and therapists fall in line and “teach to the academic curriculum” so that students may pass state proficiency exams knowing, in many cases, that what is being taught has little relevance to the student’s current and future life needs? And what about the stress experienced by both students and parents when there is too great an emphasis on academics? For parents who have reservations about the quality of their child’s school program, how does one strike a balance between expressing concern and working towards change within school systems, while at the same time maintaining positive, trusting and collaborative relationships with those who may have the longest and most enduring affiliation with their child outside of the family?

Finally, how do families and practitioners strike the balance between addressing an individual’s limitations and challenges related to autism, yet appreciate and embrace the fact that any individual has relative strengths and abilities? How do we go about identifying motivations and building strengths and talents, rather than simply trying to remediate weaknesses?

In collaboration with parents, persons with autism, and professionals, I have just completed a documentary film entitled *Autism: Communicating in Another Way* that addresses this very issue of identifying and building interests, strengths, and talents. In making this film, we struggled with striking the balance between the need to identify interests and build strengths and talents for

persons with autism, while not “sugar-coating” autism and the challenges it engenders for families and individuals who live with autism.

Fundraising—How Do We Allocate the Funds We Raise?

More central to the very purpose of the popular Autism Speaks Walks, and all fundraising efforts, is the issue of finding balance between how funds raised in these types of events are used. Put simply, what is the appropriate balance in funding research versus funding services to directly support families and children, adolescents, and adults living with autism?

More specifically, regarding research, what proportion of dollars should go to finding the “causes” of autism (biomedical, genetic), as opposed to finding answers regarding effective treatment for autism (educational, biomedical, nutritional, and so forth)? It still strikes me as astonishing that some still talk about finding THE CAUSE, when we have known for the past 35 years that there are most likely multiple causes. And if research substantiates a significant genetic contribution, as many believe will be the case, what are the ethical implications for treatment or prevention?

Another area of great challenge is finding the balance between funding research or services directed towards individuals at different stages in life. It is no secret that research and treatment dollars in autism have been directed disproportionately

towards children, most often young children, for the past three decades, compared to those directed towards adolescents and adults. We must find a better balance. Soon, the young children will be adolescents and adults, after all. Are we ready to give more balanced attention to quality of life issues for those persons with autism who may live at least two thirds of their lives beyond the age of 22?

Finally, there has been passionate discussion about finding the balance in using funds for national initiatives as opposed to grass roots organizations that provide supports and services to families throughout the country. I have worked closely with one such organization for almost 20 years, Community Autism Resources in Swansea, Massachusetts and have seen their struggles to maintain the funding stream that supports their very fine programs for local professionals and families. We cannot allow these grass roots efforts to waste away. National organizations such as Autism Speaks serve important purposes to educate the general public, lobby to change policy, and raise awareness. But grass roots organizations also serve important purposes, such as guiding and supporting families *now*, for individuals of all ages.

In finding balance, I would like to suggest that we do not take an “either/or” approach, but rather an “and/also” approach in all of these areas of funding. In recognition of this need, Autism Speaks has recently established a Family Services Committee that will allocate funds for direct services

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to families and to local agencies serving families. This is an important first step in the quest to achieve balance.

Finding Balance in Attitudes and Beliefs about Autism

Another area that has become an issue of great controversy, and most certainly in need of a more balanced perspective, is our attitudes and beliefs about autism, and the experience of persons with autism. In our documentary film, we begin with two quotes:

The first is from the book *Evidence of Harm*, by David Kirby. In the foreword of his book, Mr. Kirby states:

“Autism is a hellish, lost world”.

The second quote is from the mother of a nine-year-old son with autism, posted on her website:

“Some call it autism; others call it despair and sorrow. I happen to call it hope, beauty and fascination”.

How do we come to terms with this great divide? Surely there is a need for common ground and balance.

Is autism a “disease” that needs to be eradicated, or is it a different way of experiencing the world? To be clear, this is not about minimizing the challenges experienced by families and persons with autism. It is about how families and practitioners make meaning out of the reality of autism in their lives. I have a number of adult friends with autism who are able to talk about their experiences. Some say they would want to be cured if a cure was available, while others say their autism is so much a part of the essence of who they are as people, that if they were cured, they would be totally different people. Clearly, there is not a simple right or wrong answer, but the schism that exists in the community of autism has unfortunately created, at times, a culture of divisiveness,

rather than a helpful dialogue to promote greater understanding and acceptance of different positions. Somehow, we must strike a balance.

A related issue is how families cope, adapt, and grow. Is autism simply a tragedy for the family, or is it an opportunity for all of us to grow—parents, family members, and practitioners? Is it a disease to be cured, or a difference in development that creates many challenges, but for many parents, does not change their appreciation for the person with autism in the family?

In my career, I have heard many parents communicate the following message:

“If we could go back and change our lives, we would not wish that our child be “normal”. We have grown in so many ways and have been blessed with the most wonderful people who have come into our lives. It has not been easy, but we have lived life more deeply.”

This is not to say that parents who feel this way have a more “noble” position, just a different experience from families who strive to cure or “recover” their child from autism.

We are now painfully aware that “quick fixes” do not exist. Goodness knows, the field of autism is inundated with quick answers and unsubstantiated promises. In most cases, it probably is more productive to think of the journey of having a child with autism, or supporting people with autism, as a marathon, and not as a sprint to the finish line. As part of this journey, taking time to reflect on the challenges, many of which are related to the difficulties in

finding balance, should provide food for thought that will nourish both parents and professionals. The ultimate goal is to move closer to finding balance in our family and work lives.

As for the larger initiatives of advocacy and fundraising organizations, let’s all encourage and support their efforts to find the proper balance in supporting individuals with autism and their families. However, let’s not shy away from providing constructive suggestions to help them stay on a balanced course.

I’d like to conclude with a quote from the great “prophet” Woody Allen –

“80% of success is just showing up”.

So take the time to turn to members of your family, your professional colleagues, and all others who show up, help to provide balance, and improve the quality of life for people with autism and families. Shake their hands, give them a hug, and say, “Thanks for caring and for showing up”. 🍷

Editor’s Note: The original version of this article was presented as a keynote address at the Southern New England Autism Speaks Kick-off Luncheon Walk, summer, 2007.

BIO



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 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.