

## BOOK REVIEW

### *“Beautiful Ben: My Son with Autism”*

By Sue Lehr

Reviewed by JANET DUNCAN

Browse the shelves of any chain bookstore these days, and you will find a number of family narratives featuring a child with a disability—especially a child with autism. Autism is common enough that most people have at least a passing awareness of it, based on personal experiences with friends or family members. In a genre with so many books and perspectives, *Beautiful Ben: My Son with Autism*, by Sue Lehr, is an extraordinary personal account of her family life that will leave the reader wondering if they ever really knew anything about this disability, or, for that matter, family life itself.

Lehr provides us with an unflinching look into the life cycle of an entire family while they learn about Ben, each other, and what it means to be educated in this society. Ben is the backdrop for their interactions and decisions; and while autism is a major emphasis of the book, it is not the sole definition of Ben. Through numerous vignettes we learn about what it means to have autism, Ben’s particular version of autism, and how this family keeps moving forward regardless of the latest insult or triumph, to find a “normalcy” that defies convention.

To put Lehr’s book into a societal context, it is helpful to understand the evolution of the field of special education toward inclusive education, advocacy for persons with disabilities, and the present day tenets of community living for persons with significant disabilities. In the classic books, *Cognitive Counseling for Persons with Severe Disabilities* (1984), and *Learning to Listen: Positive Approaches and People with Difficult Behavior* (1996), Herb Lovett taught us to think about individuals with significant disabilities in a new way: that people with significant communication impairments, behavioral problems, and physical and cognitive disabilities yearn to explain to us what the problem or situation is, if only we can listen and pay attention. Lovett challenges us to rethink what it means to have a “severe” disability, reminding us that a real person is inside, and that we need to find out how to communicate with this person.

At the same time, Anne Donnellan (1985) brought forward a significant theory called the *criterion of the least dangerous assumption* which demands that decision-making for, and on behalf of, a person with a severe disability needs to be based on human dignity and the understanding that we must assume competence for the

individual. Failure to do this is dangerous, and leads toward a slippery slope of poor decision-making and outright dehumanization. Adding to this assumption of competence, the notion of all behavior as serving a *communicative intent* by Donnellan (1985) and others, recasts our erroneous interpretations of maladaptive behaviors, intelligence, and human dignity of risk.

Lehr's narrative unfolds against the backdrop of the shifts in approach to disabilities beginning with the 1960s, coinciding with the rest of the Civil Rights movement, and continues into the 1980s, when the dawn of human services and "normalization" took off in the United States. Previously, to have autism as a child meant relegation to segregated services, institutionalization, and likely an early death. Horrific stories about these experiences are chronicled in such books as *The Willowbrook Wars* (Rothman & Rothman, 1984), *Inside Out* (Bogdan & Taylor, 1994), and *The State Boys Rebellion* (D'Antonio, 2004).

Early in the book we learn about Ben as a youngster, attending the progressive campus school and being accepted by peers who recognize his humanity. For those who are interested in the beginnings of "inclusive education," where children with and without disabilities are educated in the same class, this book is filled with examples of best practices, as well as the downside of blazing trails for others. Ben was a student most people simply did not know what to do with, so many tried their best, sometimes with devastating results. There are examples of teachers accepting Ben without hesitation; while others could not imagine in their wildest nightmares ever teaching a student as complicated as Ben. Then there are other teachers who took it in stride, making educated calculations with and for Ben, and providing him with a first-class inclusive education in Syracuse, NY.

Lehr tells us about the personal toll the litigation with their small town school district over Ben's education took on their other children. Facing enormous pressures to "just go away" and take their son with them, they chose to remain, and held their school district accountable. Looking for better opportunities for Ben, they enrolled him in a city school district program that was to become a flagship program for best practices for educating students with autism. Again, it was not smooth sailing by any means. We learn of yearly negotiations with teachers and administrators, as Ben moved forward toward graduation day. Community-based programs, academics, and functional academics, all played a key role in his education, and each year the family renegotiated Ben's program with the next set of new faces. This is a common experience for families of children with disabilities (Duncan, 1998), where each school year poses a new series of problems and dilemmas in education that other parents do not have to manage. In a way, the Lehrs became "professional parents", learning all they could from the best in the fields of Psychology, Education, and Rehabilitation. They were uniquely positioned as professors in a college with access to new ideas, adding to their own understanding of the situation.

Ben was one of the first students to use facilitated communication in 1989-90, and the resulting commotion this caused was strongly felt by the family. First, Ben was now in the eye of the national media as a sensation, falling into the savant role as a person with autism who could now communicate deep thoughts and emotions. Second, what Ben revealed through his typing was horrific. He was being abused by a trusted assistant at school. Third, having something to say meant that he was now regarded differently by everyone. Did he want this or that to eat? What did he think about politics? How about taking a class in biology? Trying to negotiate new expectations with his newfound literacy and intelligence (in the eyes of others) was daunting.

After graduation from high school, Ben embarked on a series of career choices that were coordinated by human service workers, some with success, while other jobs fell apart. Here we learn about *person-centered futures planning*, a concept developed by John O'Brien and Connie O'Brien in the early 1980's (Holburn, Gordon, & Vietze, 2007) and how an agency supports Ben in his desire to lead a typical life. Each time, the Lehrs try to determine with Ben what he really wants to do, and how best to accomplish the supports to make his dream a reality. While it isn't always easy, and bad things do happen, it is striking that they persevered with Ben and did not settle for anything mundane simply because it was 'safe' for him. Life is filled with risk and rewards, and Ben has had every chance to fail and succeed with his actions.

In the human services jargon, this type of risk-taking is called "dignity of risk." It means that parents sometimes have to stand back and let their child do things that may be considered dangerous. Without having an opportunity to fail, and try again, one is never truly alive. From Lehr, we learn about Ben mastering the use of power tools. We learn about Ben living on his own, in his own home. We learn about encounters with the police and the public that don't go well. At every turn of events the reader develops an appreciation of Ben as a pioneer in his own community.

Through all this, the Lehrs do not lose focus. They are as deeply committed to supporting Ben as best as they can, in conjunction with the enormous talents of many others who are equally committed to Ben. For those of us who are inclusive special education advocates, this book is a clear reminder that our work is not done. If a family such as the Lehrs, given their professional expertise, available support, community, and other resources, experience difficulty in educating and advocating for their autistic son's independence, then it is not difficult to imagine the odds faced by others who lack these resources. Imagine how the disabled citizens of other nations live in poverty, without education and health care, and without human dignity. It is imperative that we consider how the United Nations Convention on the Rights of Persons with Disabilities represents a huge step forward in recognizing individuals with disabilities and their inherent right to basic necessities and freedoms we all enjoy and how this contrasts with the daily experiences of people with disabilities. One realizes after reading *Beautiful Ben* is that Ben is privileged,

loved, and cared for by his family and community. His story is uplifting; and we are equally privileged to learn from him and his family.

### *References*

Bogdan, R., & Taylor, S. J. (1994) *The social meaning of mental retardation: Two life stories* NY: Teachers College.

D'Antonio, M. (2004). *The state boys rebellion*. NY: Simon and Schuster

Donnellan, A. (1985). *Classic readings in autism*. New York: Teachers College.

Duncan, J. (1998). Here we go again: Lessons from school about Facilitated Communication. *Facilitated Communication Digest*, 4(3), 4-6

Holbun, S.,;Gordon, A., & Vietze, P. M. (2007). *Person-Centered Planning made easy. The PICTURE method*. Baltimore, MD: Paul Brookes.

Lehr, S. (2009). *Beautiful Ben: My son with autism*. Tully, NY: Arimenta.

Lovett, H. (1985). *Cognitive counseling for persons with severe handicaps*. Baltimore MD: Paul Brookes.

Lovett, H. (1996). Learning to listen: *Positive approaches and people with difficult behavior*. Baltimore, MD: Paul Brookes.

Rothman, S. M. & Rothman, D. (1984). *The Willow Brook wars*. NY: HarperCollins.

UN Convention on the Rights of Persons with Disabilities. (2007). Retrieved November 19, 2009 from <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/Convention.aspx>