



Things to Think About!

Ability vs. Disability By Gary Shulman, MS. Ed.

***Editor's Note:** SNRP periodically accepts articles for publication from outside sources. Mr. Shulman is a knowledgeable individual in his field with a perspective we felt worth passing on. Linda Jorgensen, SNRP Executive Director

During my more than 24 years as Program Director of Social Services and Training Coordinator for Resources for Children with Special Needs and now as a private consultant and trainer, I have had the great pleasure of asking thousands of parents of children with disabilities to tell me about their children's talents, skills, abilities and passions. Very often that question has been met with astonishment, "Someone is actually asking me to **accentuate the positive**", as the old song says! What a concept! My heart has always been warmed and my soul and spirit uplifted by the myriad responses that gleefully utter from the lips of these proud parents: "Susan is a gifted musician-she hears a song once then sits down and figures it out on the piano", "My son swims like a fish!" "Thomas has memorized the entire subway system-he is passionate about trains.", "Hector always greets me with a hug and seems to know when I am feeling down-he brightens up my life."and on and on. My response is to have everyone in the room praise and applaud these positive stories of hope, joy and delight. We of course also move on to discussing the needs, wants, wishes and dreams.

I often tell the story of an "angel" who blessed this world by the name of Matthew. When Matthew was born, the doctor who had obviously not been through any sensitivity training, felt compelled to tell the new parents the bad news that after conducting genetic testing, Matthew was determined to have a very rare condition called I-Cell Disease. "So what does that mean?-when can we bring Matthew home to enjoy and love him?" The doctor proceeded to elucidate that Matthew should not be brought home but rather institutionalized! He then felt compelled to share that Matthew's immunological system would over the course of 5 or 6 years, destroy all organs in Matthews tiny body. "Why put yourself through such misery-he will never grow or develop. Needless to say these spiritual, caring, loving dedicated parents took Matthew home and received Medicaid under the Medicaid Waiver program to meet many of his complex medical needs. He was enrolled in Early Intervention where his miraculous and talented Occupational Therapist Ilaine, only saw the potential skills, talents and strengths. Matthew learned to happily feed himself, walk with a walker, sing, dance and love.....oh how this child gave and received love. He was pure love. This beautiful child

positively affected ever human being who was fortunate enough to have the joy of knowing this angel on earth. I made him pancakes during one visit and he stopped eating for a moment, turned his steroid filled, barely moving body, to face me so he could tell me, "Hey Gary! These are delicious!" Matthew by the way had a photographic memory and could tell you every player in the Yankee dugout, give you directions to Grandma's house and direct you to all food items in the supermarket.

There is no miraculous ending here-Matthew died after 6 glorious years on earth. Six years of love and joy. Six years of enhancing the lives of everyone who was fortunate enough to have known this miraculous child. At his funeral were all the friends, neighbors, family members and admirers whose lives had been touched by this angel of humanity. The doctor who had diagnosed Matthew of course was not present. His memory lives on in every workshop I conduct. His parents graced me with a gift that I will always cherish. Knowing that Matthew would soon be leaving this world, they had him record anything that he wanted to say to those people in his life whom he cared for. Sitting on my dresser is a small photo book with Matthew's picture in it. There is a button in that photo-book. When you press that button, Matthew's sweet voice can be heard saying, "Hello Gary-I love you!" His spirit helps to motivate all parents of children with disabilities who have been told by "professionals" what their children would never be able to do. Just as the Bumblebee should not fly according to scientists, yet does (because nobody has ever told the bumblebee he can't fly) so too will all children with disabilities continue to FLY as long as we continue to recognize that behind every label of disability there is a human being with abilities, talents, skills and passions.....and love to give and receive. We must never take the hope away!

Behind every child with a label of disability is a child with ability to be cherished, praised and supported.

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