

## Successful Adaptations for Learning to Use Touch Effectively

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### My Son Ben

By Terry Boisot

#### [From the Beginning: The Importance of Touch](#)

My son Ben was born September 20, 1989. I remember the first time I looked into his face shortly before he was whisked away by the hospital nurse for the tests that newborns are given. His left ear was bent temporarily from the position he had been lying in for so long in the womb—his face looked like it had been squeezed in an unnatural position. I touched his face and knew he was happy to be born—happy to be out in the world with me. I could feel it in my own hand.

It wouldn't be too many hours after his birth that I would be told the pupils of his eyes were white—very dense "cataracts" was the diagnosis. Years of many eye surgeries ensued commencing from the day he turned two weeks old. Ben has worn contact lenses from he was one month old. When he was 18 months old, Ben was diagnosed as profoundly deaf—he doesn't respond to sound the way one would expect and his brain does not translate sounds the way it should.

Ben was three years old when he got his first wheelchair, five when he was placed in his stander for the first time, and six when he made the first step in his walker. My son is deaf, blind, developmentally and physically disabled.

From the time Ben was a newborn, instinctively his sister, who is three years older, and I spent hours holding him and our touch was never far away. When our absence was necessary, Ben was never without a soft stuffed animal that was easy for him to wrap his little fingers around. When he was only a few weeks old, a pediatrician whose expertise was in the development of children with visual impairments watched him in his stroller and said, "I have never seen a baby have such a close bond to a stuffed animal like Ben."

Ben has always had a real dog to play with ("tug-of-war" is usually the favorite), a cat to hold while feeling the rumble of its purr, and he is usually encouraged to reach out and feel a tree before we pass it on a walk, and touch the flower while smelling its scent. He is connected to the world he sees and hears little of, because of touch.

#### [Introduction to Manual Signs](#)

Around the time Ben was three years old, our family was advised to begin communicating with him by using co-active sign language—wherein his hands were physically guided to produce adapted signs from American Sign Language. Ben's interest and receptivity was remarkable and further connected him to his surroundings and the people in them. An instructional assistant whose

background included knowledge of sign language supported his receptive communication in school. To better understand Ben's different learning needs, this assistant received regular training from his teacher credentialed in the deaf and hard of hearing area, speech and language therapist and teacher credentialed in visual impairment.

## **Inclusive Education**

Since preschool Ben has been fully included in the regular classroom of his neighborhood schools. His classmates have been taught sign language and how to communicate with him through the efforts of his educational team (teacher credentialed in the deaf and hard of hearing area, instructional assistant who signs, and other special education professionals). Today, some of those children have become remarkably skilled in the use of sign language and their experience will hold many rewards in the building of accepting communities everywhere in the future.

## **Making Use of Sensory Cues**

As Ben matured and around the time he was in fourth grade, he was less interested in being touched intimately by our hands in his, and he seemed to develop other ways to understand his surroundings – perhaps by using a combination of his weak sense of hearing and sight, with a strong sense of smell and feel. I can only watch, and it is a truly amazing thing to observe if one spends the time. In the outdoors, Ben guides the direction of his wheelchair by the warmth of the sun, the shadows of the trees, the singing of the birds, and the smell in the air. He is confident and connected to his world, and I know why.

While his maturity would not allow a close personal touch, his desire to know what goes on around him guided our understanding that he desperately needed touch and tactile tools to receive information and learn to communicate. Naturally, his family and friends give him cues as to what is going to occur next. For example, a simple tap on his shoulder to let him know that it's time to turn, presenting him his swim trunks to hold five minutes before it's time to go in the pool, giving him the dog leash in his hands to understand we are going to walk the dog, and so on. But this is not enough.

## **The Importance of Proper Positioning**

It is important to note that Ben's ability to reach out deteriorated significantly in the fifth and sixth grades. Not because he couldn't learn, but in part because his body had become larger, and his positioning in his wheelchair was not adequate to hold him securely and enable the freedom of his hands. Ben exerted a great deal of energy because his seating was poor, and his dislocated hip caused him tremendous pain that we were unaware of at the time.

With the repair of his hip, and months of working closely as a team with his inclusion teacher, general education teachers in junior high school, program supports, special educators, occupational and physical therapists and others that know him best, seating has improved, giving him the freedom to learn with his hands once again.

## **Developing Tactile Communication Cards**

Since his body prevents him from forming accurate signs with his hands, more formal forms of tactile communication have been developed for Ben under the guidance of Project Salute and June Downing at California State University, Northridge. Handmade tactile communication cards are used consistently between home and school representing a thing, a place, an event or a person.

**Communication with Ben's inclusion teacher is imperative in making this work. The inclusion teacher often visits our home; we spend time visiting for at least 20 minutes before the beginning of each school day, and have regular contact via email. Ben must be given time to feel the tactile card and either feel or experience what it represents, repetitively, respectively, and consistently throughout two days. Most importantly, his body must be positioned in a place he feels secure—in his wheelchair or lying down flat. Yet at times he gets annoyed at the simplicity of the communication and finds entertainment and great pleasure in pretending not to care; when we, his family and teachers, care so much. He is after all a teenager and a boy.**

## **Developing Self-Determination**

**Today, Ben's life is enveloped in opportunities to touch, receive information and make choices. Typically, he is not pushed randomly in his wheelchair without receiving a verbal and touch cue as to the direction he will be headed, and he is not expected to transition from one activity to another without a tactile and verbal warning. Daily, he is presented with choices tactilely and visually; such as, what clothes he wants to wear or what he wants to eat first. Sometimes the choice he makes is simply not to make a choice, but to watch and laugh at the rest of us squirm and ponder our best approach or feel anxious about the time. To me, this is a sign of self-determination and I usually smile inside.**

**When Ben's family and teachers have an inherent respect that he does learn, give him the proper time to process what is expected of him, and he is presented tactile communication tools in a consistent manner throughout all aspects of his life; then Ben's choices become clearer to everyone and his selections do not seem just random.**

## **A Team Effort**

**Tactile communication tools are developed in partnership with Ben's educational team, therapists, and me, his mom. We meet at school, talk over the phone, have regular meetings, and brainstorm via email. Teamwork assures consistency in the use and presentation of the tool.**

**The biggest challenge for us is being sensitive to what material or design should be used in making the tools for Ben's optimum use and understanding. We must often ask ourselves this important question, "Is this material or design identifiably different by touch from others we have used?" Does the rubber on one card that represents his wheelchair feel similar to the material from his flotation device placed on the card that represents swimming? This is hard—our hands not as sensitive as Ben's even when our eyes are shut. We rely upon the counsel of Ben's teacher credentialed in visual impairments and Ben's reaction upon presentation.**

**There is little doubt in my mind that his communication will one day burst out into the world for all to understand. The quality of his future depends on it.**

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