

Over my lifetime, having had to go for doctor appointments, for numerous health related issues, I have had many experiences both positive and negative, which have impacted my life. What may dramatically hinder or provide the care of a patient is the attitude of the health professional. Those who really were of help were professionals who listened first and then gave their advice. Time and again, in the position life has found me, the ones who positively have provided care are professionals who were willing to hear our frustrations and think outside of the parameters of their text books.

Presenting professionals with a disability that is not diagnosed as a particular syndrome has meant many misunderstandings of my abilities. There is a need to have the whole picture in view to see the combined details. Really to respond to details without the full picture is missing the intent of the artist. With the individual there not only is purpose but also potential which must be appreciated in order to help the patient. Hoping to discover the contributing factors of my disability has given doctors much thought but unfortunately many have missed the contributing factors of my ability.

When Ruth, my speech therapist, began therapy with me the light of hope was illuminated. Her vision was not obscured by a general perception of a non-verbal child. Instead she gathered information by studying me as a complete person. Through this thorough investigation she made discoveries which changed the course of my care and ultimately my life. (There cannot be development and growth if the fundamental understanding of the patient/client is flawed, nor can there be appropriate treatment if hidden conditions are missed.) Giving me continual comfort and hope in counsel and therapy she provided positive professional help throughout my developing years.

Not having a voice very often has meant watching professionals notice anxiety prompted behaviours and make their diagnosis based on assumptions. When the paediatrician gave his assessment "he's mentally challenged. No amount of medication will help this child.", the hopelessness was overwhelming. Who can benefit from a desperately negative, pessimistic caregiver? Proof beyond reasonable doubt translates into a chance for a disabled person to have opportunity to prove they have abilities, not only disabilities. We give criminals in our society this defence and yet I have experienced the "absolute guilty" verdict in regard to being mentally challenged and having no intelligence. Why is this acceptable in the medical field but not in a court of law? Through listening and careful observation of a patient, discoveries of conditions meet with hidden abilities, which give the patient hope and a feeling of self worth.

When conversation wholly stems around choices, both involved are conversing on a very superficial level. As a boy without a voice those that provided equipment presented options that generally gave choices of foods and very general topics and most were picture symbols. When given only childish symbols the true communicating of thoughts and feelings becomes

behaviours. This unfortunately translated into being “bad” or “mentally challenged behaviours”, in my experience. There cannot be true, valuable communication when the conversation is perpetually considered meaningless on one side and given no degree of constructive thought. Wholesome intelligent conversation must be conducted as a two way street providing both individuals with opportunity to speak their thoughts. The communication system of pic symbols, designed by a person who has always had the ability to speak, shows a lack of understanding of how frustrating it is not to be able to express intelligent thoughts and feelings.

More consideration has to be given to acceptance of parent’s observations and insight into their child. Perhaps they seem convinced their child is very deserving of more respect regarding abilities, but professionals often feel they are just in denial of the child’s problems. Having fought through countless appointments and meetings of hopeless diagnosis and future development my parents had to be optimistic and believe in their children to give us the positive support to become fulfilled in abilities we have been blessed with.

Choosing acceptance of abilities in light of the condition can benefit both the patient and the professional. Every individual is born with a purpose, chosen by their creator, and it has been most concerning in my life that many practitioners have chosen to disqualify my gifts and abilities. Despite their very narrow views, regarding my body’s inability to control motor skills, I have developed my writing skills and used my photographic memory to fulfill graduating requirements and make my voice heard. If those professionals had given me the hope of this, life could have been so much easier and, they could have learned from me for the help of other children. There is always the heartfelt benefit of giving hope to others and hope is what gives life meaning.

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