

## Brief Encounters from the Taos Institute, September, 2009

### A Collaborative Conversation

Thoughts by Dr. Robert Cottor



Eight years ago, my wife, Sharon, and I were very excited to visit our son and his family in London for the Christmas holidays. We were especially excited to see our youngest grandson, Ryan, who was then eight months old. However, Ryan's parents had become concerned because Ryan was still unable to roll over, sit up or pull up on his own even though he was an alert, vocal, happy and engaging little boy. After we had spent a short time with Ryan, we realized something was very wrong. Clearly, we needed a "Ryan doctor." Within a week, we obtained a diagnosis from a pediatric neurologist who told us that Ryan had spinal muscular atrophy, a progressive genetic neuromuscular condition that would result in the irreversible paralysis of his voluntary muscles. There was no treatment for this disorder. Ryan's prognosis was that he would not live more than two years. The world totally changed for all of us.

We were challenged by the need to construct new realities and a way of living that could "successfully" deal with this unimaginable situation. We immediately began a very difficult conversation together, exploring how we could shape a good-enough future for all of our family within our new world created by Ryan's genetic condition. This conversation was extended to include all family members. We saw this collaboration as necessary for our being able to construct a future that would include the constant caretaking that Ryan required and the dramatic changes in thinking, feeling, behavior and activities that his condition and its circumstances would inevitably generate. The taken-for-granted expectations for living that Ryan's parents had prior to his diagnosis could no longer be guidelines for this family with two young children. We talked about how important it would be for all of us in the future to be able to look back and describe how Ryan's life, however short it might be, had expanded our lives and had provided new opportunities for learning, relating and positive action in ways that we had never imagined.

We imagined how we could shape a meaningful and rewarding future for all of our family under these new conditions that had been suddenly imposed upon us. The unknown, the uncertainty, was very scary but we committed ourselves to move into the future with appreciation, courage and collaboration. We brainstormed about the many practical changes in family living that would be necessary -- continual medical care, expensive medical equipment, the logistics of Ryan's individual care and family support, preparations for Ryan's death -- as well as our son's

career, where they could live with Ryan's special needs and how their family could live together successfully under the conditions created by Ryan's spinal muscular atrophy. We also addressed how our relationships with each other might change and the new responsibilities we would have within our network of relationships.

This collaborative conversation, this way of envisioning and planning for the future, has continued since that time. Ryan's family soon relocated from London to Arizona where the extended family lives. The challenges continue. Ryan is now eight years old and is in third grade. He is very bright, articulate and compassionate. He remains a happy and very engaging child. His diagnosis is unchanged but his life is not his disorder. Ryan has had some very close calls medically. He requires 24-hour a day care. He attends school regularly. He gets around in a power wheelchair. His parents are incredible caregivers. His brother is his best friend. His extended family is available and supportive. Love is a very strong bond.

When Ryan's parents returned to Arizona, they founded a nonprofit with the goal of creating a freestanding pediatric palliative care and respite care facility for children and their families who are coping with life-limiting conditions. This concept of care is very new in the United States. The community's support of this project has been incredible. ***Ryan House*** is currently under construction and will open in Phoenix early next year. It will provide care to children and their families free of charge. Without question, new realities and new possibilities, never before imagined, have been co-constructed over the past eight years by the opportunities for positive and generative action that Ryan's story has offered our family and our community. Many, many people are benefiting from Ryan's very special life journey. As Ryan says, "Hope is hope -- either you got it or you don't." We have all learned to appreciate life and what it can offer to us if we are willing to construct positive futures no matter what the circumstances may be. We are very fortunate to have Ryan in our lives.