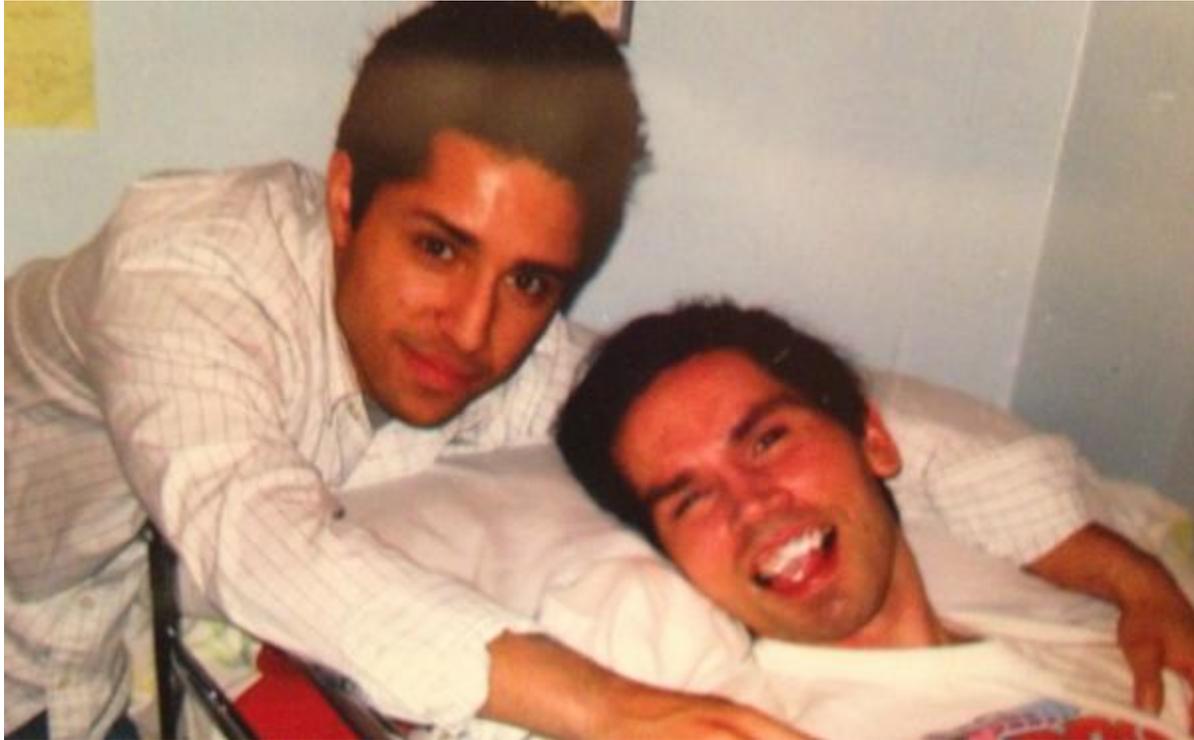


Sam Murillo



Sam Murillo - October 2012

Sam Murillo a Family Navigator with Family Voices of Colorado is November's Person of the Month. November is "Family Caregiver" Month and Sam is representing an important and often overlooked segment of the disability community—siblings of people with disabilities.

Sam, 32 is a native of Denver, is one of four boys. He is married to Emily Murillo, a social science researcher. Two of his three brothers have disabilities. His oldest brother Robert was seven years older than Sam and had a lifelong seizure disorder. Robert had Huntington's Disease which became very disabling at age 20. This genetic disorder is rare for a child and presents like ALS. Robert died from this disease in 2007. Sam has two younger brothers as well, one of whom has Schizophrenia. Like many people with childhood onset schizophrenia, he had severe learning disabilities that were never diagnosed or treated. Because of this, Sam says his younger brother struggled in school and was treated as a behavior problem. He ended up self medicating and developing a drug addiction—a common story for people with serious mental illness. His younger brother was not diagnosed until he was 23, after which he was able to stabilize and get treatment (he has only been clean for 17 mos). The youngest brother of the group does not have a disability.

Sam is a Family Navigator at Family Voices of Colorado (www.familyvoicesco.org) and says this job is an alignment of the stars -an ideal job for him because he gets to use his skills and passion. He spends a lot of time at Children's Hospital in the neurology and rehab department. He grew up seeing what seizures do and also seeing the failures of systems to meet the needs of

families. His father was adamant about the need for Sam to get an education. Sam earned his Master's Degree in Social Work from the University of Denver after earning a Bachelor's Degree from Northwestern University of Notre Dame.

Living with disability clearly shaped his life. Sam clearly comes from a very strong family and if there is a "right" way to raise children with and without disabilities together Sam's parents did so. Sam credits his upbringing to making him a well rounded person but also sees his entire family as more balanced and healthy due to their experience with disability. Sam says that his life with his disabled brothers caused him to be able to think about social justice and systemic issues from a very young age. He recalls in fourth grade musing over questions such as why he was one of very few students of color at his private school or wondering what caused bullying. Advocacy was clearly in his blood from a very young age—he recalls instinctively reacting to bullies even when doing so caused him to take a beating. Sam grew up believing what we spend lots of time trying to convince the community--disability is a normal part of the human condition.

When asked to describe his older brother, he used the word superman—the adoration of a younger brother still resonating in his voice. I asked Sam if his decline and increase in disability diminished the superman like qualities. Sam replied that it was the opposite. Sam described his brother as "the most tender human being" he ever met and said that even when he lost his ability to talk that his attitude lit up a room. While it was very difficult to watch his beloved older brother lose abilities such as the ability to work, to walk, to work out, and to watch the emotional struggles that all of us with acquired disabilities go through, Sam said that Robert handled his disability with grace and dignity. Sam describes his family atmosphere as one with very high expectations fortified by an environment filled with love and laughter. He tells a story that during transfers (that took two people because Medicaid was not approving Hoyer lifts in those days) Robert would flip Sam off while their mother had her back turned. Sam would be a typical kid and tell his mother but when their mother would turn around Robert would have his hand down looking angelic. However as his disability progressed he was not able to move his hand as quickly so got "caught" but they continued the game—and always laughed about it.

It was not all fun and games; when Robert learned at age 13 that he had Huntington's and would deteriorate then die young he attempted suicide –and Sam found him then turned to drugs before coming to peace with himself as a man with a disability. Sam said for years he would sneak and follow Robert around and go to places where he knew Robert would go, such as the neighborhood rec center and would tell people about Robert's disabilities, asking them to keep an eye out for him and explain what a seizure might look like, and what they should do. He did this to preserve the dignity and independence that was so important to his older brother. Sam knew his brother did not want their parents on his back but also knew instinctively that some assistance was really necessary.

I asked Sam if it was a burden to provide so much care—many in our mutual field of Social Work would say that having a teen provide physical care or even other support for their sibling is not good—they use the word "parentification" and that means that they think it puts children in the role of parents—and that doing so is very bad for children. Sam disagrees that this is bad and says that the way his parents handled it was not damaging at all, but rather very empowering.

Not only was Sam part of the care (his mother was tiny and his father working so often Sam was the only one strong enough to effectuate a transfer) but Sam also would attend IEP meetings for his brothers. As a kid going to the same schools Sam had a better idea than any parent could about the day to day trials and tribulations experienced by his siblings. Sam stresses that it is important that taking on this role should be voluntary, encouraged through empowerment and strength development and should never be forced on a child or teen and certainly should not be due to refusal of state systems to provide appropriate support. Sam clearly felt empowered to be part of the care.

Because of the systemic barriers, the need to have to fight for adequate medical care, appropriate services and an education, parents of disabled children are often overwhelmed, both emotionally and financially. This leaves the non-disabled often taking a back seat. Sam acknowledges that while he was well loved and knew his family cared, that his needs were not ‘front and center’. Sam says it was not until he was 30 (he is 32 now) that his parents could take the time to ask him about his day—before that they were too consumed with the needs of both brothers. He contends that he did not need as much attention. He was a good student, active in sports, and engaged in other activities such as school clubs. His parents were not always able to attend his events, but always made it sure to support his academic pursuits. His father as an immigrant was sharply focused on education and was determined that Sam get a top notch education. When the time came to go to college there were two choices—one local and one out of state but to a better school. Sam did not want to leave, he worried his brother would die while he was gone and that he would lose his place in the family system. Not only did his father encourage him, but his brother—his personal superman—encouraged Sam to go away to college. Sam says that while he had responsibilities at home he was always allowed and encouraged to have his own life. Robert promised Sam he would hang on while Sam was in college and kept his promise. During the years Sam was away his brother lost his ability to speak and it haunts Sam to this day that he cannot remember his brother’s voice. Sam lost his brother two days before starting graduate school.

While Sam has fond memories of his brother he did discuss one MAJOR flaw—his brother was a Raiders fan, something Sam as a Denverite found baffling.

I asked Sam what advice he has for parents who are raising today’s siblings. Sam stressed that the strengths of each family members should be used and nourished, that siblings should be part of the solution but also allowed to have a life of their own. He emphasized that high expectations for children with disabilities is super important. Sam was able to develop his role as a supporter, as an ally and an advocate from a young age because his parents played to his natural strengths and allowed him to participate in the care for his older brother. Sam describes this as a very empowering experience. Sam says parents must communicate openly about what the disability will look like, what it is like now and what may change in the future. Children should know how important their impact on the family can be—for Sam that value helped build his self esteem and create the man he is today. He says expectations must be openly communicated and each child must be allowed to have a life apart from the expectations around the disability of their sibling, but also be empowered to play a role of care.

I asked Sam what the disability community could do to assure siblings that they are welcomed. I asked him about the lack of siblings in the community—there are many parents but few siblings. Sam said that we need to openly let them know that they are welcome. He recalled that when he started his job at Family Voices he was worried that he would not be accepted because he was neither a parent nor a person with a disability. He hopes that the community sees the siblings for the expertise that they do have.

I asked Sam what he thought “family centered services” meant? He said this is not a new concept for us in the disability world, but is only now coming to light as a way to provide services. He said it means a holistic approach that merges medical needs with a social model. He says it is about helping the family thrive and should not be about mere survival. He said that professionals need to always remember that the only reason there are services, policies and systems is because of the individuals and families. This knowledge should always be where all policies, decisions and discussions start and end.

Sam has become a member of CCDC and attended our advocacy training. It has been a pleasure to work with Sam on a variety of health policy issues. While soft spoken, professional and exceedingly polite he is a fierce advocate in his own right, developing his own style. Sam is a valued part of the team of us who do health policy work on disability issues and is frequently part of important committees involving Medicaid issues. Sam is one of the people making up the next generation of movers and shakers in the disability community. CCDC is honored to work with Sam and look forward to continuing our relationship with this extraordinary man.