

In Celebration of World Down Syndrome Day – March 21, 2012

- by Laurie Smith

My very first thought on my very first day volunteering with adults who have disabilities was, “uh oh!” A squat farmer with Down syndrome barreled toward me and enthusiastically shouted something like, “min-re-lay, fiddy-fie, bostus, THAT DID IT!” Dick Sutherland seemed delighted to meet me but I was terrified—I could barely understand a word he said.

This sense of discomfort, often tinged with pity, tends to shape our view of people with Down syndrome. We assume the worst—that they struggle constantly and hold little hope of achieving a “good life.” Or, when joy glimmers from the tell-tale eyes of a person with DS, we find it cute, like when kittens nuzzle in a heap. Neither view is complete.



A simple new blood test for Down syndrome, administered in a woman’s first trimester, lends urgency to the debate about whether adults and children with intellectual disabilities can enjoy a high quality of life. Fortunately, recent research from Children’s Hospital in Boston challenges our naïve notions of people with Down syndrome. In a survey of families affected by DS, 79% of parents reported a more positive outlook on life because of their child; 99% of the 284 individuals with Down syndrome surveyed said they are happy with their lives. Even with a small sample size and significant selection bias, these results are a revelation: individuals with Down syndrome can lead happy, meaningful lives in spite of society’s often pained, patronizing response to them.

My friend Dick Sutherland was a perfect example. He made plenty of sense once I took the time to listen carefully. Dicko had the good fortune to live in a community called L’Arche, a network of homes for disabled individuals around the world that strives to “make known the gifts of people with developmental disabilities, revealed through mutually transforming relationships.” In many ways, Dicko was an average guy: he packed his lunch every evening, read the Bible, worked devotedly at a job that didn’t pay much, dearly loved his friends, and followed baseball fanatically. As a man with Down syndrome, Dicko also lived differently: he crafted his peanut butter, jelly, and cheddar sandwiches with ritual zeal each night, he only recognized a smattering of words in his well-worn Bible, he worked with other adults with disabilities, befriended his caregivers, and earnestly expected Ken Griffey Jr. to appear at his birthday party every year.

I grew to love Dicko for the way he bellowed, “THAT DID IT” to convey frustration or delight. I respected his incredible work ethic; I admired his crafty efforts to get his own way. As friendship blossomed between us, we held countless mock-wrestling matches and followed the Red Sox with devotion and dismay. Dicko even took to cleaning my bedroom. He color-coded

my belongings and heaped them onto precarious mountains of red, green, and blue. He grunted with glee as he worked, seeming to admire his clever tidying and clearly taking pride in his gift to me.

Not long after I ended my stint volunteering in L'Arche, my father died. I was told that when Dick heard the news, he buried his face in his arms and cried. When he regained his composure, he said simply of me, "she my friend." Those remain the sweetest, most meaningful words of comfort I ever received. Dicko himself passed away in 2007 at the age of 63, a stunning lifespan for a person with DS.

Today is World Down Syndrome Day and across the globe people like Dicko, along with their families and friends, are celebrating the myriad gifts those with DS have to offer. Events such as art exhibits, morning teas, and school dress "down" days are intended to push past our prejudices and showcase how individuals with Down syndrome live today. In a hopeful sign of serious engagement, the United Nations is hosting a Down syndrome conference in New York.

Down syndrome shaped Dicko's life in countless ways. It determined where and how he lived. It appeared indelibly in his balloon-ish face and garbled speech. At times, his disability caused him anguish. Yet I believe that Down syndrome enabled Dick to love in extraordinary ways, lavishly and loudly, to express a joy and enthusiasm that "ordinary" adults are expected to subdue.

I honor Dick on World Down Syndrome Day because I believe that every person with Down syndrome has something to contribute and something to say, regardless of how confusing or terrifying their words may sound. I am enormously proud to say of Dicko, "he my friend."

Laurie Smith is an educator and mother in Vermont who lived and worked in a L'Arche community for four years, supporting and sharing daily life with individuals with intellectual disabilities.