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# Humanum

Issues in Family, Culture & Science

WITNESS

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## Four Fathers

DAN LAHOOD

*As he went along, he saw a man who had been blind from birth. His disciples asked him, "Rabbi, who sinned, this man or his parents, that he should have been born blind?" "Neither he nor his parents sinned," Jesus answered, "he was born blind so that the works of God might be revealed in him." John 9:1-3*

By way of introduction I should say that my wife and I have operated St. Joseph's House for the last 32 years. SJH is a Day Care and Respite Care home for children with multiple disabilities. In addition to this work we, along with other like-minded people, founded a Ministry called Isaiah's Promise. Isaiah's Promise supports families who have decided to carry their child to term after receiving a poor pre-natal diagnosis. If the defense of life at every stage is a seamless garment, we like to think we have added a few stitches to its making. The bulk of the stitching, though, is the work of the families who demonstrate the love and courage to welcome the life they have been sent.

At the beginning of our ministry we had no idea where any of this would lead. It was and is chaotic, joyful, inspirational, wearying, sad, edifying, instructive. It is a life we could not have imagined but one we now cannot imagine having not lived. Mother Teresa was reported to have described a child with a disability as the "treasure of mankind." That may be apocryphal, but we have found it to be absolutely true. Many of the kids who came to our home over the years have died, but every year at Christmas their parents return. And they tell us how they miss their son, their daughter. They tell us, not in so many words, that the love they had for their child was the life they could not have imagined before their child arrived; but one they could not have imagined not living once the child was here. This is true for the Isaiah's Promise parents as well as the Saint Joseph's House parents. Not one carries any regret, whether their child lived for minutes or decades, that that person was part of their lives. Their life to them was a Gift, a Pearl of Great Price, if you will.

Let me try to convey the depth of this love by sharing a few of the stories of parents and

children we've had the privilege to know. Bobby was deaf, worked two jobs—at Walter Reed Hospital and at a nursing home—as an orderly and had a beautiful wife, Mary, who was also deaf. She likewise worked at the same places. They had two children, Bobby and Carlos. Both were severely disabled, unable to speak or walk. They communicated minimally using sign language. Bobby and Carlos came to Saint Joseph's House for respite for 15 years or so. As the boys grew, we noticed that Bobby was growing too. “Hey, Bobby,” we tried to finger-spell, “you been working out?” “Yes, I have to be strong to lift the boys.” He looked like Superman. His boys weighed over a hundred pounds and he lifted them effortlessly. He would swing the heavy wheelchairs into the cart behind his van which he used to transport them. A few weeks before his death, he knocked on our door. I did not recognize him. I could see he was turning yellow beneath his brown skin. He weighed a hundred pounds. He wrote on his pad, “I bought steroids at the gym. I wanted to be strong. I have liver cancer. I am dying.” At his memorial service, his best friend quoted Bobby: “I will not let the world throw away my boys like trash.”

George and his wife had a daughter with severe Cerebral Palsy, and George was largely responsible for her physical care; he was devoted to that work. He did not have a wheelchair van when he would pick her up at Saint Joseph's House. He would lift his daughter out of her chair and put her in the back seat. I could see the strain on his face and would always say, “George, let me give you a hand.” “No, this is my job.” After his death, we learned that George had a heart defect that killed his father in his late thirties. He knew he had the same condition. It killed him at fifty. But day in and day out, he lifted her, changed her diaper, bathed her and loved her to the end.

Jay is a musician, a very fine musician, good enough to have auditioned to be Tony Bennett's accompanist. Jay had a daughter named Katie who was compromised, having an unknown twin that died some time before she was born. Jay is full of life and he showed the most life when he was with his daughter, told her dumb jokes, bad puns and would sing “If I Only Had a Brain” to her at the drop of a hat. He practiced his piano with Katie in a wheelchair by his side and Katie would smile, roll her eyes in wonder and would get grumpy when he stopped. After Katie died at 21, I was returning some dishes to their house after the funeral reception. Walking up the driveway I heard nice piano music. The closer I got, I heard not just the notes but the emotion that poured from Jay's fingers. I heard him play a lot, but not like this. This kind of beauty, this art, could only be a product of a depthless love. As quietly as I could I left the dishes on the porch and stole away.

It was Easter Sunday and Pope Francis was greeting people in the Square. He saw Dominic in the crowd and walked over to him. Dominic has Cerebral Palsy and was being held by his father, a professor at Providence College. Francis took the boy from his arms, brought him close and kissed him. Bobby, George and Jay would have repeated this gesture a thousand times, more than that. A 77-year-old man did this. Then we saw the Pope's embrace of the man covered with tumors. I don't know the scientific name... I thought he was kissing the Elephant Man. Afterwards, the man was quoted as saying, “I felt like I was in Heaven.” The joyrides Francis takes with young adults with Down Syndrome around St. Peter's testifies to this same spontaneous love and acceptance. (It helps apparently to wear a Lionel Messi jersey if you want him to stop!) The last I'll mention was a stunner for us. The Pope had encountered a young family with an Anencephalic baby the week he was in Rio for World Youth Day. According to reports, the parents had approached Francis, told him their story and asked for his Blessing. They told him that doctors, family and friends had urged that they abort their child. They resisted and sought out the Pope to tell him their story and receive a Blessing. Anencephaly, a fatal condition, is the most common we encounter in our work with Isaiah's Promise. At the Mass to close World Youth Day, during the Eucharistic Procession as the Gifts were brought forward, the announcer said, “A young family was asked by the Pope to bring

their child who is disabled to the altar.” Twenty-seven years ago our child was diagnosed *in utero* with a fatal condition called Polycystic Kidney Disease. Like the young family in Rio we were urged by doctors, certain family members and acquaintances to get an abortion. We resisted and it changed our lives forever. We, like Bobby and George and Jay and Francis, with the Grace of God, came to see our children's lives as a Gift.

The miracle that led to Paul VI's beatification was the healing, *in utero*, of an unborn child. Doctors found that the fetus had various conditions “incompatible with life” and urged the parents to abort their child. This is a common experience for the families we encounter at Isaiah's Promise. This intervention from Heaven is a clear indication to the Church and the world that the “poorest of the poor,” the child diagnosed with a disability in the womb, is not outside the ambit of God's Love and Mercy whether they are healed or not. He seems to say, “You care for them now and I'll care for all of you later”—a perfect riposte from Blessed Paul VI, an Apostle for Life, to the all-too-common attitude that rejects out of hand those found to be “defective.” Paul VI's miracle amplifies Pope Francis' admonition made at Assisi. In meeting with a group of kids with disabilities and their caregivers, he said, “Their wounds need to be heard.”

When fathers live their vocation heroically, when they support their family in every situation, when they love oblivious to society's judgments and when men and women of goodwill come to recognize and support them in their witness, the culture of exclusion will become the culture of embrace.

*Dan LaHood, along with his wife, operates St. Joseph's House, a day care and respite home for children with multiple disabilities. He is also co-founder of Isaiah's Promise, an organization which provides support, information, friendship and hope to families who decide to carry their children to term after receiving a severe or fatal prenatal diagnosis.*

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