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Chairman of Special Olympics

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The Bitter Truth

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Last week, *New York Times* reporter, Danny Hakim <u>discovered</u> the unmistakable pattern of a crime -- the suspicious death of Jonathan Carey, a series of questionable actors who were close to the deceased at the time of his death, a string of denials by those close to the scene, refusals by those same actors to speak on the record, and a medical report that points to foul play. What may have shocked readers however, is that the crime was not discovered in an underworld mob family or in a drug cartel but among the State of New York's caregivers for people with intellectual disabilities.

Did the State of New York kill Jonathan Carey?

Probably. Carey was a 14-year-old with autism who was under the care of the State. The likely perpetrator was an employee of the state. The denials are coming from leaders in the state. The outrageous likelihood is that the State did kill Jonathan Carey. And the even more stunning reality is that such a crime against a person with intellectual disability is far from rare around the world.

Last week, the World Health Organization (WHO) confirmed that New York is just the tip of the iceberg. After 30 years of bypassing the health of people with disabilities, the WHO has now reported what has been obvious to people with intellectual disabilities around the world: people with disabilities are an enormous and growing population and their care and support is in crisis. The medical profession is ill equipped to care for them, governments are largely ignoring them, and most interventions designed to help promote public health and education fail to reach them. In most developing countries, care is abominable. Jonathan Carey's tragic death from neglect and mistreatment is almost certainly being repeated daily around the world.

How is it possible that more than three decades after the United States began to desegregate schools for people with intellectual disabilities, more than two decades after the United States passed the Americans with Disabilities Act, and five years after the United Nations adopted the Convention on the Rights of Persons with Disabilities, a massive dignity deficit remains? The bitter truth is that subtle but persistent discrimination against people with intellectual disabilities remains rampant around the world. Sadly, most people still perceive a person with an intellectual disability as incapable of contributing to his community and thus, treat her as a liability that is all too easily ignored. The language we use is revealing: they are "in-valids", "retards", "dis-abled".

It's a short distance from that type of discrimination to abuse and even murder, but it's an equally short distance from empowerment to dignity. In recent months, the eyes of the world have been mesmerized by courageous activists in the Arab world as they seek to validate their own dignity in the face of oppressive regimes. They have deployed novel tools -- Twitter, Facebook, and other social media -- to carry out a new kind of social revolution: a Dignity Revolution. The most compelling message of those protests wasn't about technology or even about political parties or economics. It was the sign held by a single Libyan man carrying his homemade sign reading, "Ana Rajul;" in English, "I am a man." He had caught and was spreading the dignity virus.

I wish I had his name so I could make him an honored guest at the next stop on the Dignity Revolution, the largest gathering of people with intellectual disabilities in the world, the Special Olympics World Games in Athens, beginning July 25th. There, 7,500 people of all ages from nearly 180 countries will return to the home of the ancient Olympics to compete in sports. But make no mistake. They are also coming with an unmistakable determination to lead a dignity revolution all their own -- to attract government leaders, health care professionals, educators, sports organizations, educators and perhaps most importantly, average citizens of every age and color to their own global movement. Their goal is the most difficult of all revolutionary goals: to change people's attitudes, to open people's hearts.

But nothing less is sufficient. Changing laws and rules is necessary but not sufficient. Desegregating spaces or organizations has never been an adequate response to fear and discrimination. Adopting conventions and improving funding formulas has never been enough to change the way people think and feel. For those who seek dignity, governments and their structures are often an obstacle but they are rarely the totality of the solution. The real engine of acceptance and dignity is your neighbor, your classmate, your colleague at work. Governments can't force them to think more openly or to see dignity more universally.

The real source of Jonathan Carey's death is us -- all of us who have considered him and his fellow human beings with intellectual challenges to be less deserving of dignity. The real source of the world's most powerful revolt against that long and painful history of indignity is the voice of empowered people with intellectual disabilities. They aren't as likely to have as many articulate representatives as other groups -- or a sophisticated social media infrastructure behind them, but they each proclaim "Ana Rajul." They have open hearts, courage in their attempt to be seen, and most stunningly, a magnetic authenticity. Theirs is a dignity revolution unlike others, destined to reshape not just the laws of nations, but the hearts of people.

If the world listens, tragedies like Jonathan Carey's death will become less likely in the years ahead. Joining this dignity revolution would be the only reasonable way to pay our respects to his short and undignified life.