

Special Child, Future Luxury?

Book review of Life As We Know It: A Father, a Family, and an Exceptional Child, by Michael Berube

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On a September day in 1991, a silent and purple James Lyons Berube entered the world. “He looks Downsy around the eyes,” said someone in the delivery room. With these words, his young family plunged into the world of disability, beginning with a harrowing three weeks as baby Jamie fought for his life in Intensive Care while his parents and five year old brother absorbed the reality that this was not the kind of baby they had expected.

Had Jamie been born a generation ago, doctors would have told his parents to put him in an institution. In those days, professionals labeled such children “Mongoloids” and “idiots.” The public and professionals viewed these children as hopelessly damaged creatures whose presence in families and society would undermine the lives of “normal” members.

For the Lyons-Berube family, institutionalization was never an option, not only because the practice is (thankfully) no longer the norm, but also because Jamie was always a vital and cherished member of the family. As chronicled in Life As We Know It, written by Jamie’s father, Michael Berube, the family has fought for Jamie’s needs and acceptance every step of the way, from his struggle for survival in the intensive care nursery to his receiving occupational therapy to help him adapt to kindergarten. Through that process, Jamie has emerged as a little boy with a sense of humor, a package of likes and dislikes, and a disposition all his own. In other words, Jamie is a person. To most of the rest of the world, however, Jamie’s personhood is obscured by the diagnosis conferred by the extra chromosome he carries: he is a “Down Syndrome” child, a “retarded” child, a “disabled” child.

Life As We Know It presents Jamie to the world, and in the process challenges our prejudices, our notions of normalcy, our conceptions of what makes people valuable, and our sense of obligation to others. With distinctive wit, Berube comments that, “Jamie has no idea what a busy intersection he’s landed in: statutes, allocations, genetics, reproduction, representation—all meeting at the crossroads of individual idiosyncrasy and sociopolitical construction (p. xix).”

Following the roads radiating from Jamie’s intersection, Berube explores the foundations of our views on human difference in general and on Down Syndrome in particular, in biology, philosophy, linguistics, politics, and social ethics. Some of these sections, that Berube interweaves with the family’s narrative, can make for slow going. The relevance, say, of the differences between trisomy 18 (Edward’s Syndrome) and trisomy 21 (Down’s Syndrome), or the philosophical path from Plato through Wittgenstein to society’s construction of children like Jamie, seemed at times somewhat abstruse. These analyses are thoughtful and provocative, however, and the end notes provide sources and references that enable the reader to check facts and to delve more deeply into the vast array of science and considered reflection that Berube taps.

A professor of English at the University of Illinois at Champaign-Urbana and the author of several previous books and essays, Berube is a wonderful writer. He is open and lyrical when writing about his family: the harrowing first year; Jamie's relationship with his older brother Nick; the Berube's efforts to cope with many emotional and practical challenges; and their passionate efforts to provide Jamie with every therapeutic, learning, and social experience that might propel his development. Most eloquent of all is Berube's evocation of Jamie. One cannot read this book without coming to care for this lovely child.

In Life As We Know It, Berube wears his political heart on his sleeve. He argues strenuously for privacy to make deeply personal decisions such as whether to have prenatal testing or to abort a Down Syndrome fetus. He decries the policies that increase the wealth of the rich while reducing programs that provide essential educational and therapeutic services to the disabled. He exposes the moral questions that lie behind each budget cut or redefinition of eligibility, as when he exclaims: "What does it mean to have the technological capacity to care for the 'disabled' without the political will to do so? What does it mean that we have developed a society in which people with Down Syndrome can flourish as never before (thanks to antibiotics, modern surgery, and/or early intervention programs) but in which they are too often denied the chance to flourish?...I fear this above all: that children like James will eventually be seen as 'luxuries' employers and insurance companies cannot afford, or as 'luxuries' the nation or the planet cannot afford (p. 53)." These arguments have personal urgency. As the father of a child with Down Syndrome, politics and policy translate directly into his child's prospects for a life of value and meaning. By extension, they also translate into the particular lives of millions of "disabled" children and their families.

Perhaps the most important lesson of this book is that no human being, whether born with 46 chromosomes or 47, can be written off with moral impunity, for the concept of "disability" is a human construction. Berube argues that as a society we can choose to define "normalcy" and "disability" as narrowly or as broadly as our political, ethical, and economic agendas demand. In this era of shrinking public responsibility, tax cuts, and "managed care," narrowing definitions of disability are inevitably to be expected. With wit, honesty, and grace, Life As We Know It invites the reader into the Berube family and challenges us to take a hard look at our changing social contract and what it says about ourselves.