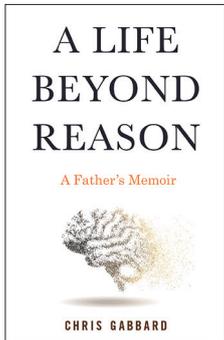




Book

A woe of ecstasy



A Life Beyond Reason:
A Father's Memoir
 Chris Gabbard
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What gives human life its value? According to Enlightenment philosopher John Locke, it is the ability to be conscious of oneself and surroundings, and to be capable of abstract thought. Like many, Chris Gabbard believed in the ideals of the Enlightenment and had faith in human rationality. But when his son, August, was born with severe brain damage, he came to question the idea that the capacity for higher reasoning is the defining feature of humanity, and he explores how this experience challenged him and his rationalist beliefs in his memoir *A Life Beyond Reason*.

In the early hours of March 5, 1999, Gabbard's wife, Ilene, entered labour and their son was born in what would later be described as "a classic case of obstructed labour", resulting in a hypoxic-ischaemic brain injury. August was profoundly mentally handicapped, prone to seizures, and unlikely ever to walk, talk, or develop cognitively beyond the level of a 1 year old. But when Gabbard first saw his son lying in the intensive care nursery connected to a ventilator, he experienced a "shamanistic, peyote-induced separate reality" in which he hallucinated "everything from the infant's perspective, forty-two hours in a matter of seconds". And his perspective on the baby was transformed. Before he saw August, Gabbard felt it might be best if the baby died, but in that moment August "appeared to be magically beautiful, the most amazing, radiant being I had ever beheld, [encompassing] the infinite and the eternal".

Their lives changed radically that day, and caring for August became the central focus for Gabbard and his wife. However, August's arrival also prompted a radical philosophical rethink for Gabbard. Raised Catholic and sufficiently devout to have considered the seminary, he rejected the Church as a teenager after struggling with the question of why God allows suffering. Over the following years, he became a dedicated atheist and materialist, dedicated to the Lockean ideal of the rational individual. However, August's need for constant care showed Gabbard that "it was absurd to build a society on the fantasy that everyone should depend solely on oneself". Similarly, although he had believed Socrates' maxim that "the unexamined life is scarcely worth living", this implies that the life of a person incapable of self-examination, like August's, is inherently worthless.

Gabbard and his wife rejected this view. They loved their son, because for them "he wasn't all that different. He was August, just one member of a quirky family." They became devoted to "cultivating whatever gave him pleasure, be it food, music, or taking him for rides in an oversized baby jogger". As their worldview changed, Gabbard became involved in disability activism, although as a parent of a child with severe mental impairments, his needs often did

not fit well with those of the rest of the activist community, whose focus was on removing social barriers that prevent people with sensory or mobility impairments achieving independence. Many within the disabled community are suspicious—and often rightly so—of the motives of parents of disabled people who attempt to speak for them, although in Gabbard's case he did so primarily because August wasn't able to speak for himself.

Gabbard sought an alternative model of disabled rights that applied more readily to people like August, in which the disabled child's dignity and right to life were recognised. This right to life is by no means a given, and Gabbard became involved in a campaign against philosopher Peter Singer, who argued in favour of euthanasia for disabled children like August. When Singer spoke at Gabbard's university, Gabbard argued that Locke himself opposed euthanasia for those unlikely to develop the capacity for abstract thought, if only to err on the side of caution. Although Singer conceded the point, Gabbard felt his case relied on philosophical technicalities and that he had let down his fellow campaigners; it would take him several more years to find the philosophical arguments he needed. The concept of care also required a reformulation in the light of August's condition. Gabbard argues for a concept of "caring labour", which emphasised mutuality and interdependence, where care-giving "was not an expression of selfless idealism" but something he did because August made him happy, and because Gabbard needed him as much as August needed his father. This leads Gabbard to reject Locke's perspective in favour of another philosopher, Martha Nussbaum, who argues a severely disabled person's most important qualities are those that link them to the rest of humanity: the ability to love, to relate to others, the capacity for perception, and their delight in movement and play.

Raising a severely disabled child is a very challenging experience, although most people tend to focus more on the labour involved, emotional strain, and financial cost. The idea that it might challenge a person's philosophical or spiritual beliefs is rarely considered. Gabbard felt that his experience caring for August was best summarised with Emily Dickinson's quote: "a woe of ecstasy"—that caring for August brought a mess of contradicting feelings: pain, hardship, frustration, love, and joy. Despite the hard work and stress that August's disability brought, Gabbard's life with his son was full of tender and beautiful moments, and he argues convincingly that caring for a disabled child became the masterwork of his life and was an experience of profound beauty.

Robert Stirrups