Acceptance, Avoidance, and Ambiguity: Conflicting Social Values about Childhood Disability

ABSTRACT. Advances in medical technology now permit children who need ventilator assistance to live at home rather than in hospitals or institutions. What does this ventilator-dependent life mean to children and their families? The impetus for this essay comes from a study of the moral experience of 12 Canadian families—parents, ventilator-dependent child, and well siblings. These families express great love for their children, take on enormous responsibilities for care, live with uncertainty, and attempt to create “normal” home environments. Nevertheless, they experience social isolation, sometimes even from their extended families and health care providers. Their lives are constrained in many ways. The challenges faced by parents of technology-dependent children raise questions of justice within society and within families.

Because of advances in medical technology, children who need part- or full-time ventilator assistance to breathe can now live at home rather than in hospitals or institutions. This is the outcome desired by most of their parents, as well as the parents of those with other special health care needs, but the challenges of technological dependence are often daunting to families (American Academy of Pediatrics 2005).

All children are dependent on adults for care and nurture. These children, however, are dependent on both adults and machines. Although not tethered in the same way as the children, the parents and siblings also depend on these machines. What does this way of life mean to the children and their families?

In reflecting on the ethical aspects of this topic, how might I begin? If I were a philosopher, I might quote Rawls and the hypothetical “veil of ignorance” that underlies his theory of justice. But I am not a philosopher.
If I were a physician, I might point to my primary obligation of beneficence to my young patient. But I am not a physician. If I were a social worker, I might stress the importance of supporting the whole family when a child has complex medical needs. But I am not a social worker. If I were a policymaker, I might emphasize how many needy groups and worthy causes compete for scarce resources. But I am not a policymaker.

What am I then? A writer, a person involved for many years in bioethical issues, the director of a project on family caregiving, the wife of a man who has been quadriplegic and brain-damaged since an accident 16 years ago, the grandmother of a child with severe cerebral palsy. Where else can I begin but with poetry?

Seamus Heaney’s poem “St. Kevin and the Blackbird” (Heaney 1996) turns an Irish legend into a meditation on sainthood. St. Kevin, so the story goes, was kneeling one day in his tiny cell, so constricted that one of his outstretched arms extended out the window. A blackbird landed on his palm, settled down to nest and lay her eggs. Kevin,

. . . Finding himself linked
Into the network of eternal life,
Is moved to pity: Now he must hold his hand
Like a branch out in the sun and rain for weeks
Until the young are hatched and fledged and flown.

Heaney then abruptly brings us back to reality:

And since the whole thing’s imagined anyhow,
Imagine being Kevin. Which is he?
Self-forgetful or in agony all the time
From the neck on out down through his hurting forearms?
Are his fingers sleeping? Does he still feel his knees?
Or has the shut-eyed blank of underearth
Crept up through him? Is there distance in his head?
“To labour and not to seek reward,” he prays,
A prayer his body makes entirely
For he has forgotten self, forgotten bird,
And on the riverbank forgotten the river’s name.

To make the connection of this poem to ventilator-dependent children explicit, as Eva Feder Kittay (2004) has done in the context of profoundly intellectually disabled children, families in these situations are often lauded as saintly, although this is a designation few would accept. Saints are expected to make sacrifices, to suffer in silence. Yet even saints hurt and ache
and forget who and where they are, and why they are doing what they are doing. And as tortuous as was Kevin’s “link into the network of eternal life,” in a few weeks the little blackbirds flew away, healthy and free. Not so ventilator-dependent children and others with lifelong disabilities. People can more easily imagine being Kevin—carrying out a short-term heroic act—than being the parent of a disabled child and committing themselves to a lifetime of unremitting, mundane acts of devotion and care.

BACKGROUND OF THE MONTREAL CHILDREN’S HOSPITAL STUDY

The impetus for this essay comes from a study of the moral experience of 12 Canadian families caring for ventilator-assisted children at home (Carnevale et al., in press). The study, conducted by a multidisciplinary team from the Montreal Children’s Hospital, followed 12 families who had been caring for such a child for at least three to five years. In all, 38 parents, children, and siblings participated in semi-structured interviews, collectively and individually, and were observed at home. (A few families had more than one affected child.) The children, who ranged in age from under 2 to 19, required ventilator assistance for a number of reasons—central hypoventilation syndrome, myopathy, muscular dystrophy, spina bifida, or obstructive apnea. Four of the 12 children were ventilated through tracheostomies and 8 through face masks—all except one of the latter was ventilated only at night. The families were French Canadian—a few were of English background—and were mostly middle or lower middle class.

The study’s primary objective was to document and analyze the “moral experience” of these families, not in categories given to them but as they defined and commented on the issues. Some of the issues they raised were treatment decision making, both in terms of the process and then of living with the decision; poor communication with health professionals; lack of understanding from extended family members that created a sense of marginalization; and the need to be advocates for their children as well as themselves because they were “pioneers” in new and uncharted territory. Out of themes like confronting parental responsibility, seeking normality, conflicting social values, living in isolation, and questioning the moral order, the researchers identified “daily living with distress and enrichment” as an overarching phenomenon. (See Carnevale et al., in press, for a full description of the study methods and findings.)

The families are served by a provincial health care system that is relatively comprehensive and generous. In Québec, Local Community Health
Centres (CLSCs) provide front-line care to patients in their communities. CLSCs are mandated to assist persons at home with a wide range of needs. Home care services can be provided by a range of health care professionals and may include nursing, nutrition counseling, occupational therapy, physiotherapy, respiratory therapy, speech therapy, and social services. Support services are also available to family caregivers. Financing is determined on the basis of a standardized evaluation, and a case manager is assigned to coordinate services. Nursing and other affiliated health services are free; a minimal number of hours of support services can be allocated and financial aid is available to those requiring more support services than can be provided by the CLSC. For cases of complex care at home, however, even this comprehensive set of services often falls short of the full coverage that may be required.

DISABILITY AND DEPENDENCY

Values can be defined as the social and political choices and preferences that determine how people act as individuals or as a society. In this context, there is a conflict between the value of including all people in society’s benefits, with whatever accommodations and expenditures are necessary to make that possible, and the disvalue generally placed on disability and dependence. In simplistic terms, it is a conflict between acceptance and avoidance, with a lot of ambiguity in between.

It is perhaps a sign of progress that such conflicts even exist. In earlier generations, people with disabilities either did not live very long or were kept out of sight at home or in institutions. If their appearance was unusual enough, they were given sensational names like “The Elephant Man” and displayed in circuses and medical schools.

Disabled people in non-Western societies are sometimes described as more accepted than in North America, but this is a partial and highly romantic view. A few studies, for example, in Northern Mexico and Botswana, indeed have shown that disabled children may be particularly valued as gifts of God. But these instances are rare. In cultures where shame is a prominent value, disabled children are considered retribution for the family’s sins. In cultures that believe in reincarnation, the child herself may be held at fault for transgressions in a previous life (Groce and Zola 1983; Ingstad and Whyte 1995). In the many areas of the world where even healthy girls are considered less worthy of family resources and attention than boys, what chance does a disabled girl have for the services and education she needs? According to the United Nations and UNICEF, disabled girls are twice or
three times more likely to experience sexual and physical abuse than their non-disabled peers. And where the ability to contribute economically is essential to family survival, disabled children have little value, other than as objects displayed for pity and money. The most common employment around the world for disabled people is begging (Groce 1999).

We in resource-rich North America consider ourselves more enlightened, but perhaps we are less so than we like to think. Although people with disabilities are far more visible in communities, as workers, and in the media, there are still large gaps in equal access, support services, and opportunities. People with disabilities or conditions that make them look “different” still encounter attitudes that are demeaning and degrading, or thoughtless and insensitive. The movie “The Station Agent” presents a sensitive portrayal of a dwarf who prefers watching trains to interacting with people. His self-imposed isolation is so intense that he initially resists the friendship offered by two people who in their own ways are also isolated. The viewer feels his pent-up frustration when, in a moment of drunken fervor, he climbs on the bar in a tavern and shouts to the patrons: “Look at me! This is your chance! Look at me!”

An interviewer talking to Peter Dinklage, the actor who plays the station agent, asked, “In the movie, people walk by and make comments. Does that really happen?” “Oh yeah, every day,” Dinklage responded. He has a good sense of humor, he added, and doesn’t take it too seriously.

Isolation

Like “the station agent,” the parents in the Carnevale study also experience isolation, both self-imposed and socially created. One mother, on a waiting list for home adaptations, said, “Now I’m stuck in the house. We have a little rack with wheels for the ventilator. But it’s heavy and with the baby in your arms, you [can’t] lift it, bring the oxygen concentrator to the doorway and connect the oxygen.” Hiring a babysitter is almost impossible and respite care is scarce. Similarly, a British study of parents of ventilator-dependent children found that the majority that had tried formal respite care found the services were inadequate and that family members and friends could not help out because they had not been trained (Margolan, Fraser, and Lenton 2004).

Many parents felt isolated because they did not know other families “in the same boat.” One mother said, “I need to have people [who have been through the same situation] tell me what will happen—because I feel like I’m alone in the world.”
Some were isolated from their families who disapproved of their determination to care for their children at home.

Parents also reported feeling isolated from health care providers, many of whom were characterized as rude and hurtful. They did not feel that the advice they received from physicians was morally neutral. One mother recalled a doctor who kept referring to her daughter as “marginal.” She said, “I thought that was really low. She’s a human being first and a human being with a disability second.” A father said, “The first time we met with the doctor, he asked us, ‘Are you going to keep her or place her in a home?’” Parents were suspicious of health care providers who many perceived as dismissive of their decision to sustain the child’s life. “Whenever my daughter has to go to the hospital,” one mother said, “I’ll stay with her if they let me—because I can’t be sure that the staff will be competent. Right now, I’m fearful when they offer me services, because they’re always poisoned services.”

Parents were isolated from other “normal” families whose children progressed developmentally and who could plan for the future. They constantly worried about the possibility that the machinery would fail, that their children would die. Time was out of joint in their lives.

Normality

Despite their sense of being “different,” the parents tried to create a sense of normality in their lives and homes. Most tried to redefine normal to make it fit their children’s needs by striving for stability in routines and practices, even though this sense of stability was hard-won. Some families, on the other hand, were “on the verge of unraveling,” with each new incident significantly unbalancing a fragile system. Another way in which families sought normality was by camouflaging medical equipment so that it did not dominate the home. The ventilator itself commonly sat on a little table or stool beside the child’s bed, hidden by a cloth or towel. Compressors were typically concealed under a table. Hospital beds were covered with colorful spreads. Home adaptations for children in wheelchairs, such as ramps, were harder to conceal. Two homes had elevators installed, one at a cost to the family of $10,000.

The concept of “normal” in this situation makes some parents ambivalent. Kittay (2005, pp. 97–98), a philosopher and the mother of a profoundly retarded young woman, eloquently describes “the social model of disability”:

Disabled people have convincingly argued that disability itself is a social, not a natural, category. Human beings come in a variety of forms, with different capacities and incapacities, abilities and disabilities, strengths and frailties.
Some of the variants are distributed over a lifespan, some are distributed differently by birth or circumstance. Neither the fundamental equality nor the fundamental dignity of humanity is impugned by these variations. The disability that is associated with bodily impairment derives from a social world which privileges some bodies over others, some minds over others, and in doing so, constructs a world which allows human capacities to flourish in some but not in others.

But even Kittay (1999, pp. 168–69) is not immune to the reactions of outsiders.

I realized . . . why it is so difficult to take Sesha [her daughter] out in public. . . . I don’t want to see Sesha as others see her. I want them to see her as I see her. The blunting of awareness of disability is part and parcel of a socialization that I, as a mother, have had to undergo—one that is a prerequisite to my socializing my child. This socialization has two parts. First I refuse to see my child as not “normal”—for what she does is normal for Sesha. Without such acceptance I would not be able to present to the world a child I find acceptable. At the same time, I have to see the child as others see her so that I mediate between her and the others—to negotiate acceptability.

**The Children’s Perceptions**

The children in the ventilator-dependency study expressed varying degrees of ambivalence about their need for machinery. They are comfortable—even happy—with their machinery at home; they know that without it they could not breathe. A four-year-old said, “My ‘pap’ [bi-level positive airway pressure machine] makes me happy. When mom takes it away from me I feel sad sometimes.” But they were wary of new situations and people. Some are matter-of-fact about requiring more family attention than their well siblings. They find their friends among other children with “handicaps”—a word they used rather than “disability,” although apparently without any of the ideological significance that accompanies the distinction among disability advocates. Many of the children, however, were reluctant to talk about their experiences, whether because they either do not see anything special about it—probably not likely for the older ones—or have adopted the family attitude of talking positively and not complaining, or whether—and this seems most likely—they really don’t know what to say about something that has been part of their lives forever.
Social Attitudes

If we as a society are beginning to be a bit more matter-of-fact about people with disabilities, largely as a result of the advocacy of people with disabilities themselves, we still are uncomfortable with dependency, of the sort that Sesha presents and the different sort that technology-dependent children present. We admire the powerful wheelchair racer, the accomplished deaf drummer, the renowned paraplegic artist, the popular blind singer. They have disabilities, to be sure, but they have overcome them in ways that society values—by having an unusual talent, by being competitive and successful, and above all by being apparently independent. (Although no person is truly independent, people with these levels of disability depend to a greater or lesser degree on assistants and devices, which are usually out of public view, for daily functioning.)

Arthur Kohrman (1995, p. 59), a pediatrician, asserts that “our culture is not particularly hospitable to (a) children; (b) children with chronic illness; or (c) particularly, children who are technologically dependent.” In my view, in the hierarchy of dependencies, children whose mechanical means of support are visible or audible are at a disadvantage. No one can see the cochlear implant that brings sound to a hearing-impaired child, but everyone can hear the computer-generated words that substitute for the familiar tones of a child’s voice. Everyone can see a person in a wheelchair. Even these devices, so common now, are less likely to cause stares and questions than a child with a ventilator or a ventilator and a wheelchair. One mother in the Montreal study said, “The kids are not mean. They’ll ask ‘What’s that? Is your machine fun?’ Adults are more often the problem. They’ll ask, ‘Does he have all his head? Is he intelligent?’”

There is something unsettling to the average person about being attached to a machine, even when the machine supports breath and life. Elderly people facing a life-threatening illness commonly say: “I don’t want to end up hooked up to a machine!” This image seems dehumanizing in a way that sitting in a wheelchair does not. The thrill of technology palls when it becomes a tether.

A few years ago The New York Times published a story about family caregiving on the front page—above the fold, the most important placement for a non-news story—that was illustrated by a color photograph of an infant with enteral (gut) nutrition delivered by an attached feeding tube. Several people, some in health care, told me that they could not read the story because the first glance at the picture was so upsetting. If they
could not even look at the picture, I thought, what would they do if they met the child or his parents?

Kohrman (1995, p. 53) says that “children attached to ventilators evoke the image of chimeric creatures: they are a combination of two different species.” The Chimera of legend was a fearful fire-breathing monster with a lion’s head, a goat’s body, and a serpent’s tail. The chimera of modern medical reality is a little child attached to a machine that helps her breathe. Kohrman’s thesis (1995, p. 55) is that “we have no clear image of who or what technology-dependent children are or of who we are as professionals caring for them.” The child becomes secondary to the machine, which demands attention loudly and vehemently. “Something is wrong,” it clamors. “Danger, danger!”

What is like for parents of such children? Kohrman asks. “What is it like to hold a child on a ventilator, listening to the damnable thing wheezing twenty-four hours a day, with the endless rattle of secretions in the child’s tracheotomy? Such an experience is hardly part of the anticipations of child-rearing” (Kohrman 1995, p. 57).

And yet, as the parents in Carnevale’s study demonstrate again and again, and as Peter Dinklage, the actor, said, “Well, you get used to it.” The problem is that a system that depends on everything working all the time in perfect order is not realistic. How many backup systems—people, equipment, supplies—must be put in place in the eventuality of a failure in some part of the system? All St. Kevin had to do, after all, was to keep his arm outstretched and let nature take care of the rest.

What becomes of families in this situation? Some parents become assertive advocates; one mother in the study worked hard to get her daughter into a school and later volunteered in the school library. Others withdraw from as many contacts as they can, trying to protect their children and themselves from the curiosity, hostility, or prying questions of onlookers. Many just have their hands full trying to get along in a world that provides some, but not enough, help, and leaves them to manage the rest. The three families that were deemed to be “unstable” were all single-mother families. Two of three families who declined to participate also seemed to lead particularly chaotic lives. Adding to the emotional strain is the financial burden, even in the Canadian system. An unexpected large expense can lead to a cascade of financial and other troubles from which a family may be hard pressed to extricate itself.
If it is fair to say that society devalues dependency, and disabilities that create dependency, then it is fair to say that dependent and disabled people are at a disadvantage. The disadvantage comes not just from their physical condition, which presents challenges by itself, but the halfway measures society takes to facilitate their full acceptance. In earlier times doors were shut firmly to people with disabilities; now doors are partly open, but it still takes resolve, determination, and persistence to push through the door. When the disabled person is a child, the person doing the pushing is usually a parent, probably a mother.

Even with all the advances in technology, medical expertise, and programs that provide comprehensive care to children with chronic illness or disabilities, there are still injustices. James Lindemann Nelson (2002, pp. 282–83) outlines three “threats to families” that arise from current trends in health care delivery. Although he specifically addresses the United States, these trends exist everywhere. The first threat is the family’s “propensity for exploitation.” When societies decide, for whatever reason, not to provide certain services or meet certain needs, the family—governed by considerations other than justice—tries to fill these unmet needs, no matter the cost to them. Knowing that families generally will provide makes it easier for health care systems not to. Alan Fleischman, a neonatologist and ethicist, points out that once some families provide extraordinary care to sick infants and children, the health care system takes this as the norm and expects all families to do the same. The family that is reluctant or unwilling may be subject to pressure and outright hostility from staff. Fleischman (1989, p. 91) says: “We ought to praise those who make great sacrifices, but at the same time should we condemn those who do not wish to or cannot provide this extraordinary level of commitment to their child? . . . Does ‘can’ imply ‘ought’ when it comes to the family responsibility for a chronically ill, technology dependent child?”

The second threat families face, according to Nelson, is a threat to their “practical identities.” Practical identities are the “things that make one’s life worthwhile,” that express the most meaningful relationships and statuses, whether that is belonging to a profession, a religion, or an ethnic group. Practical identities can be shattered by many things, including illness. What Nelson finds “threatening” is when human agency is involved in forcing change. It is not the care of the disabled child that is a threat; it is the reality that, without support, the parent cannot continue to participate in other meaningful aspects of life. Moreover, Nelson (2002,
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p. 282) says, “A family unable to foster the ability of its young to form practical identities, because all its energies are channeled into providing intensive health care or for any other reason, is truly a dysfunctional family.” Although I dislike the term “dysfunctional,” and would not apply it to the families in this study, there are certainly elements of instability and insecurity that have been worsened by the demands of caregiving.

The third threat is the tendency of family “to embody patterns of injustice” and for that tendency to be exacerbated by increased caregiving demands. What constitutes justice within a family? Does one parent take on the primary role of caregiver, advocate, and monitor? Is that fair to the mother herself and to the other children in the family? We are not accustomed to thinking of justice as a matter of intrafamily relationships. As Susan Moller Okin (1989), a political theorist, pointed out, male philosophers have usually considered the family off-limits. The family, they claim, is a “nonpolitical” entity and therefore should not be held to standards of justice. Almost all current theories of justice, Okin (1989, p. 9) asserts, “take mature, independent human beings as the subject of their theories without any mention of how they got to be that way.” Children first learn about justice from what they see in their family, she claims, and family relations should be gender-neutral, just like economic and political relationships.

But few families are truly gender-neutral. Families caring for a technology-dependent child probably have more equity in the distribution of responsibilities than other families, simply because there is so much work to go around. Yet in the families in the present study mothers appear to do the hard, daily work, sometimes sacrificing their own interests in the process. One mother took a lower-paying job to accommodate her caregiver requirements; her previous employer was not very understanding about her need for flexibility. Another mother is on social assistance; her daughter’s needs prevent her from returning to work. One father is a seasonal worker and receives social assistance when he is not working. The mother in this family has an understanding employer but when she cannot work the family suffers financial hardship.

Other children’s needs were not ignored but sometimes had to take second place to the overwhelming and pressing needs of the ventilator-dependent child. It will be interesting, if possible, to see what happens to these healthy children as they grow up: some, I predict, will be in the next generation of doctors and nurses and therapists; others will stay as far away as possible from health care.

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Nelson (2002, p. 287) concludes that “At least when prolonged and intensive family-care provision is at issue, then, reasonably affluent societies have as stringent a duty to provide families with the kind of support that will make such caregiving compatible with a reasonable chance for caregivers maintaining central practical identities, as they do to provide basic health care.” Of course, we in the United States have not achieved even that basic level of justice.

CONCLUSION

As I began with one Irish poet, I conclude with another. In “Easter 1916,” his famous poem about the Irish uprising against English rule, William Butler Yeats (1997) wrote:

Too long a sacrifice
Can make a stone of the heart.

One might be able to mend a broken heart, but not when it has turned to stone. The Carnevale study did not find parental hearts turned to stone; on the contrary, these parents expressed great love for their children and acceptance of their responsibilities. However, in their encounters with the medical system and in the community, and even at times within their own families, some parents met more than a few stony-hearted people. These judgmental individuals did nothing to share or ease the parents’ sacrifices.

Few families will be called on to provide the level and intensity of care as the families in this study. Yet most of us already provide, or will provide, some difficult care to people we love. We should be able to do so with our practical identities intact and our needs for support and guidance met. Although each family and each person within the family will have different needs and sources of inner strength, none should feel compelled or be coerced to nest blackbirds on their palms for the short term or don the martyr’s mantle for life.

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