Chapter 9

HARD TRUTHS

In 2006, the parents and doctors of Ashley X, a six-year-old with profound brain damage, sought permission to use surgical and medical procedures to permanently stunt her growth. Once the consent of medical specialists and the hospital ethics committee was obtained, physicians performed a hysterectomy, surgically removed Ashley's breast buds, and administered high doses of estrogen to attenuate her development (Gunther & Diekema, 2006).

Ashley is assessed to have the mental capacity of a three-month-old. She cannot sit upright, talk, eat, or walk. She is responsive to her environment, though, and smiles and vocalizes in her interactions with others. When she began showing signs of early puberty, her parents considered the ways that her growth would affect her comfort and their ability to care for her. They argued that the hysterectomy was necessary to alleviate discomfort and confusion arising from her menstrual cycle and that the reduction in breast size would make Ashley more comfortable when strapped in a wheelchair (as an additional consideration, the parents have stated that breast cancer is common on both sides of the family). The family contends that "Ashley's biggest challenge is discomfort and boredom and the 'Ashley Treatment' goes straight to the heart of this challenge" (Ashley Treatment, 2007). Attenuating her growth is expected to maximize her involvement with her parents and siblings by allowing her to be moved from room to room, be present at meal times, and participate in car trips and other outings. The anticipated benefits of limiting her size are psychological (it is easier to include her in family activities), physical (reduced risk of bedsores and discomfort of menses), and practical (her parents can continue to act as caregivers, thus avoiding institutionalization for Ashley and its negative psychosocial effects).

The cost-benefit analysis of Ashley's case must take into account the risks of the procedures and the concerns that they raise. Some

would suggest that it is really the parents who are benefiting from the treatment, not Ashley, and that they are in fact putting their fears and needs before her fundamental human rights (Brosco & Feudtner, 2006; United Cerebral Palsy, 2007). Further, the extreme and irreversible procedures performed on Ashley bring to mind the sad history of the eugenics movement, which forced people who were presumed to be defective to undergo sterilization procedures to ensure that their "defects" were not passed on to a subsequent generation. According to the disability rights perspective, this intervention sends the message that people with disabling conditions are unacceptable as they are and can be manipulated and deprived of natural life processes for the convenience of others (Somerville, 2007). The treatment raises particular ire among those who have suffered from discrimination, marginalization, and medical experimentation because their lives are considered to be of little value. "Stop it. We are not mice or rats or kitty cats. The final affront is to suggest that this matter is worthy of ethical attention" (Ellis, 2007, p. 419).

Ashley's family emphasizes how much they love and value her as a member of their family. The growth-limiting interventions are intended to enhance her participation in family activities, not to marginalize her and render her invisible. They refer to her as their "Pillow Angel," a reference to her sweet disposition and the fact that she stays where she is placed, usually on a pillow (Ashley Treatment, 2007). The term also appears to be coming into wider use as other families use it to refer to their youngsters in the same condition, and journalists use it in their accounts of these children (Gibbs, 2007). While the families clearly consider it a term of affection, it creates disturbing images of the objectification of Ashley and other children like her. One has to worry that such labels inadvertently permit intrusions into the personhood of these children that would be more disturbing if they were happening to Ashley, a six-year-old girl, rather than to a "Pillow Angel."

Those who support growth attenuation in Ashley's case acknowledge concerns that such processes may be misused or taken to even more troubling extremes. They advise careful screening and evaluation processes before the use of such measures. As to whose needs are being met by the procedure, advocates maintain that because Ashley is fully dependent on her parents, "the line between improving Ashley's

life and making it easier for her parents to handle her scarcely exists, because anything that makes it possible for Ashley's parents to involve her in family life is in her interest" (Singer, 2007). The rationale for the treatment is akin to the rationale for other interventions that parents permit in order to alter natural processes in their children for long-term benefits, for example, immunizations or orthodontic braces. It is also similar to other interventions intended to arrest unnatural processes, for example surgery or chemotherapy for cancer and insulin shots for diabetes. In these cases as well, long-term benefits are believed to outweigh short-term suffering.

Whichever position one takes, Ashley's case, like many of those in this book, demonstrates several hard facts for which ethical decision making offers little comfort: even sound decisions may be troubling or unpalatable, child-serving systems are flawed, resources are finite, and parents are imperfect. Let's examine these barriers in light of Ashley's case and consider the strategies by which we can advance ethical decision making despite their effects.

SOLUTIONS ARE IMPERFECT

Even those decisions made with the soundest of methods may still yield results with which people are individually or collectively unhappy. By all reports, the processes used to weigh the pros and cons in Ashley's case were thorough and fully informed. We can't determine Ashley's satisfaction with the result, but clearly her parents and the treatment team feel they made a rational decision that ultimately enhances Ashley's quality of life. Still, the interventions to attenuate her growth are controversial and discomfiting.

Sometimes decisions are "good" because they are arrived at through thoughtful, deliberative processes, not because they are unanimous, risk-free, or satisfying. Sometimes good decisions are the least bad among many choices. Professionals in any field as complex as social work must come to terms with those cases in which there are no easy answers. The fear of risks, errors, and condemnation must be offset by confidence in the process, particularly in thoughtful, shared decision making and skillful execution of the decision. Evaluation can

help to mitigate the ill effects of the decision or to improve future decisions. In Ashley's case, the decision required diverse sources of expertise to weigh the long- and short-term risks and consequences in light of her profoundly and permanently disabling condition. Those involved in the decision clearly documented and have openly shared the bases for their decisions. They feel it was appropriate, as do ethicists viewing the case from a distance (Ross, 2007a, 2007b; Singer, 2007). The fact that the decision is not wholly popular does not mean it should have been avoided or deferred. Evaluation, however, may improve future decision-making processes in similar cases. For example, it appears that no advocate with "explicit expertise in disability rights and autonomy" was invited or appointed to act on Ashley's behalf (American Association on Intellectual and Developmental Disabilities, 2007, ¶ 10). The inclusion of such a person in the decision-making process would have ensured that those perspectives were taken into account in the deliberations. Similarly, it later became evident that the hospital violated state law in performing the hysterectomy in the absence of a court order, required in all cases involving the sterilization of minors (Associated Press, 2007). Evaluation helps decision makers flag necessary steps and considerations that were not taken but will be necessary in future cases.

SYSTEMS ARE IMPERFECT

The evaluation of Ashley's case revealed a weakness in the decision-making process that can be rectified in future cases, though not in hers. Other cases in this book raised concerns about the limitations or frailties of the organizations and processes put in place to help children. Chapter 4 discussed some of the historical, political, and financial variables that limit systems' effectiveness. When service delivery falls short of aspirations, the professionals, consumers, and citizens involved must provide the critical feedback and advocacy necessary to encourage change. This is not a short or easy process, but failing to do so signals capitulation to the status quo and to a lifetime spent facing the same dilemmas the flawed system is now creating. Thus, unless fundamental changes are made to health care, education, welfare, and wage

systems in the United States, social workers and their clients will continue to confront the same intractable dilemmas with the same unsatisfying results. The vital interface between micro- and macro-change efforts becomes abundantly clear in situations such as these.

As the J. Daniel Scruggs case revealed, some systems' problems are more about the humans working in the systems than the systems themselves. When employees' egos, attitudes, jealousies, apathy, or ignorance are the cause of system failures, new strategies must be employed. Different problems call for different measures, but communication, evaluation, and education can all be used to increase workers' quality and accountability. Ethical action may involve strategies for improving systems and the people who work in them (Netting, Kettner, & McMurtry, 2004).

RESOURCES ARE IMPERFECT

Many ethical dilemmas are, at their core, problems regarding the distribution of scarce resources. While it doesn't appear that money was an overt consideration in Ashley's case, the possibility of her family continuing to provide her care rather than placing her in an institutional setting is clearly a resource issue. Some who object to Ashley's treatment have suggested that the dilemma involves more than one family's choices and responsibilities. Rather, it reveals the insufficiency of funding and supports for the many families who must care for loved ones with chronic life-limiting conditions (Grossberg, 2007). As Brosco and Feudtner (2006) state, "If we as a society want to fundamentally revise the nature of the harrowing predicament that these parents face, then, in the end, more funds for home-based services, not more medication, is what is called for" (p. 1078). Whether or not home-based services are the answer, the fundamental point is that "easy," short-term, or case-specific solutions may derail efforts to look for long-term medical, structural, and service solutions that allow families to avoid the permanent and irreversible strategies undertaken with Ashley. More broadly speaking, at what point should social workers and other helping professionals stop trying to make do with untenable resource constrictions and turn their attention to the causes of the scarcity of those resources?

Even if we accept that funds are finite and societal needs are not, questions must still be raised about the processes by which decisions are made on how to utilize fixed resources. For example, within the U.S. health care system alone, could priorities be reallocated to create greater benefits for more citizens, in the form of prevention or early intervention? Could expenditures for advertising, shareholders, executive salaries, and stadium skyboxes be better used for patient care? Why is it that states can afford to spend millions of dollars on incentives to lure corporations to their regions but feel the need to nickel and dime their social and health services? Ethical practice requires critical awareness and action regarding resource allocation issues. Social workers and other professionals must transform frustration and outrage about individual clients' dilemmas into action on the core causes of those dilemmas. This action may take many forms, including personal education, public speaking, civic participation, testimony to legislative and regulatory bodies, lobbying, and activism in movements to address societal inequities. This goes beyond the social work standard that "Social work administrators should advocate within and outside their agencies for adequate resources to meet clients' needs" (NASW, 1999, 3.07a). Rather, it speaks to the fact that a "historic and defining feature of social work is the profession's focus on individual well-being in a social context and the well-being of society" (NASW, 1999, p. 1). Ethical action thus requires attention to the environmental forces that create enduring resource dilemmas.

PARENTS ARE IMPERFECT

The media's reports in Ashley's case frequently emphasized her parents' virtues. They were described as loving, well-educated professionals concerned with their daughter's interests. Advocates for interventions such as Ashley's insist that any such case must be carefully and individually assessed. Presumably, medical personnel and ethicists would not condone such interventions for children whose parents have ulterior motives, limited care-giving capacity, deficient communication skills, or the inability to appreciate the risks and benefits involved. One wonders if parents without the same socioeconomic means, educational attainment, and other forms of privilege would

have even been offered the option of such treatment, much less allowed to pursue it. Had other parents sought the procedures, would authorities such as child protective services been contacted to pass judgment on their suitability to represent the child's interests?

Several cases in this text featured parents who are, perhaps, unlikable, unlucky, unscrupulous, or uninformed. Like the social workers in the vignettes, some readers may have chafed at the parents' decisions, and perhaps even at their right to make those decisions. As described in chapter 3, contemporary U.S. policies have attempted to balance the rights of children with the rights of their parents and guardians. Alternatives to those checks and balances come with unacceptable costs and risks. For example, who should decide what charitable gifts a child should receive, if not his parents? Where does the slippery slope end if parents are not allowed to make decisions about their child's care, privacy, or safety? As in most balancing acts, the price we pay for rights and protections is the conferral of those rights and protections in cases we may deem unworthy of those privileges.

It is sometimes easy to write off people with whom we disagree. However, effective ethical practice demands more of the professionals involved, if only for the sake of the child clients. A fundamental part of social work education involves the development of self-awareness and self-regulation and the capacity to bridge differences with client systems. In this process students learn to look beyond labels and stereotypes to understand the person behind the tough facade, laissez-faire attitude, or offensive actions. They learn to comprehend the principle of countertransference and the ways their experiences and relationships may play out in their work with clients. They are taught to understand value differences and to employ their professional values to give precedence to clients' needs. These lessons are not easy ones, and even when achieved, their impact can erode over time, as social workers contend with families who routinely and reprehensibly mistreat their most vulnerable members.

It is easy to understand how workers can lose patience and hope in light of the failure of parents to act wisely and honorably in regard to their children. Yet giving up on or demonizing parents creates significant problems for helping minor clients. Aside from exceptional circumstances, parents hold all the cards. Writing them off means

alienating the very avenue by which the worker can interact meaningfully with the child. Despite their imperfections, incorporating the parents as partners in service delivery is the means to the end of helping the child. Further, children are incredibly loyal, even to families who have repeatedly failed them. The social worker who repudiates the family may put the minor client in an untenable position of choosing sides. Not only is this unfair to the child, but such triangulation often leaves the social worker as the alienated party. Forced to choose, the child will select the familiar, even over a well-meaning stranger.

There is a final rationale for looking beyond parents' deficiencies. Many parents are victims of the same abuses and injustices that we are trying to avert for their children. Who will help them if social workers view them only as impediments and problems? Who will stand up for the families disadvantaged by unjust systems and institutional racism if we as helpers write them off? Will alienating the parents help the kids? Will it fulfill the fundamental mission of social work?

To be sure, some parents do not deserve the right to speak for their children. In those cases, social workers must act to advance the interests and safety of the minors involved, even at the expense of the parents' wishes and well-being. But many more cases are less clear. In these, the professional aim is to find ways to help kids to be heard and to be healthy, even in unhealthy circumstances.

EFFECTIVE AND ETHICAL PRACTICE IN A WORLD OF IMPERFECTION

Despite the hard realities, strategies for avoiding and addressing ethical dilemmas exist. These include focusing on long-term as well as short-term goals; speaking truth to power; refusing to surrender to stereotypes, labels, powerlessness, or hopelessness; and maintaining clarity about the core objectives. Even when we do these things, many things are out of our control, yet our development as ethical decision makers is not. The strategies to ensure a lifetime of effective, ethical practice involve awareness, alliances, attention, and action.

Awareness in this context refers to self-knowledge. For ethical decision making, it means knowing our preferences and tendencies, prejudices, values, and weaknesses. For example, do we tend to prefer

rules-based decisions? Do we typically champion the underdog? Do we worry so much about our liabilities that we avoid any decision that leaves us unsettled and sleepless? Do we habitually capitulate to authority, or do we bristle at it? Awareness asks us to be attuned to these tendencies and mindful of the ways they can subvert thorough and balanced decision making.

Awareness also requires us to think about the ways that our roles and experiences influence the stance we take when faced with ethical dilemmas. This is especially relevant to decisions involving minors. The concept of countertransference suggests that professionals unconsciously bring experiences from other realms of their lives to their helping relationships. The psychologist who was an adopted child, the physician who overcame learning disabilities and an inhospitable educational system, the social worker who investigated the death of a shaken baby, or the teacher continually berated by parents of underperforming students—each one brings those and other experiences to his or her ethical decision-making process. Awareness makes such perspectives tangible, allowing the professionals involved to use those experiences constructively and transparently, and preventing the contaminating effects they may have if they remain unexamined.

The recommendation for alliances means forging ongoing, trusting, honest relationships as a means for ethical action. This involves creating the kinds of supervisory or collegial relationships in which we can bring out our fears and frustrations and get effective advice. The suggestion that alliances should be ongoing and honest is grounded in the belief that we are most able to grow in ethical sophistication if we are comfortable examining our choices and actions and learning from them. Solid allies support us, but they also push us to know ourselves and to improve ourselves. Long-term relationships are the best mechanisms for both. Allies are also needed when ethical decisions are unpopular or when acting on a decision demands moral courage. Sometimes doing the right thing isn't the same as doing the easy thing. People who make hard, highly visible, or unpleasant decisions deserve the support of caring others.

Different but similarly important alliances are recommended for the ethical actions needed in long-term change strategies. In these cases workers can join groups, create coalitions, and contribute to

causes that address the issues that are embedded in some of the hard truths discussed above.

Attention, the third strategy for ethical effectiveness, refers to a host of efforts to keep ethics on one's personal radar. It means being alert to dilemmas, taking lessons from the ethical actions of others, seizing opportunities to learn more, and applying those lessons in new contexts. Paying attention means we look for the ethical dimensions in our daily lives, in our environments, and in the events that surround us. Consider, for example, the following situations:

- Your daughter tells you her best friend is cheating on her boyfriend. How does the ensuing conversation with her proceed when we are attentive to ethics?
- Music videos and lyrics are often condemned for slurring and demeaning others. How do we introduce ethics into a discussion of respect, civility, free speech, and artistic freedom on this topic?
- Kids in a Head Start program rampage when Santa brings hand-me-down toys to the Christmas party. How do we understand their behavior? How do we respond as their Head Start workers, as donors, and as citizens?
- Therapists portrayed on TV and in film routinely violate professional standards on confidentiality and patient boundaries. Are we alert to the effects of those examples?
- A massive school shooting mesmerizes the nation. Are we capable of discerning the ethics involved as victims and perpetrators are portrayed by the media, the events are dissected, and remedies are offered?

Perhaps this makes it sound as if ethics is a full-time occupation. This is, admittedly, not a very appealing prospect. Yet, as we contend in chapter 2, the practiced struggle with ethical dilemmas improves our decisions and our conclusions. Critical thinking is enhanced when we pay attention to opportunities to learn more and exercise the skills of practiced ethics.

The last strategy for building our ethical capacity is action. Acting on our convictions and decisions is not easy. In doing so, we may

encounter hatred, retribution, marginalization, and strife. But acting to uphold principles despite our fears is the very essence of moral courage. As Miller (2000) suggests, moral courage is also "the capacity to overcome the fear of shame and humiliation in order to admit one's mistakes, to confess a wrong, to reject evil conformity, to renounce injustice, and also to defy immoral or imprudent orders" (p. 254).

Some of us may look at the examples of whistle-blowers or other morally courageous individuals closer to home and conclude that there is simply too high a price to be paid for ethical action. Yet where are we without action? What sense is there in valuing professional or civic principles if no one is willing to stand up for them? While we may focus on the price to be paid for ethical action, we may lose sight of the cost of our failure to act. Obviously, there are ramifications for a community, a profession, or any other group when people are unwilling to speak up in support of accountability and shared values. There are implications for individuals as well that are evident when we calculate the erosion of self-respect that results from moral cowardice.

SUMMARY

Whatever the settings or populations involved, ethics is a complex exercise. There is no perfect, complete, and final recipe for ethical effectiveness. It is a process. The steps we take to have a better understanding of dilemmas and improve our decisions will surely help advance that process. Perhaps it will also help us seed strength in others. If, individually and collectively, we can avoid becoming paralyzed by cynicism, hopelessness, fear, or anger, we can encourage ethical action as well as ethical thinking. Each of us has abilities to contribute to the effort, which will, in the short run and the long run, honor the voices and choices of young people.