Chapter 8

Principles of care

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Abstract This chapter outlines the processes related to thinking about actions of individuals and groups that most enhance human flourishing. These processes are named "ethics" and they will be discussed with particular regard for the care of individuals with intellectual and developmental disabilities (IDD).

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Introduction

In the history of the field of intellectual and developmental disabilities (IDD), there has been a long-standing undertone of marginalization of people with IDD, disregard of their dignity and a trail of blatant abuses. The track record of public policy, research and healthcare in the field are replete with examples of such treatment. Families, rights activists and most importantly self-advocates are the energy behind contemporary constructs like self-determination and the ability of people with IDD to manage and direct their own lives. Review of the history and examination of the achivements of the present reflect a substantial evolution in our thinking about people with IDD and their treatment, with recognition that people with IDD, just as with the general population, must be given opportunities to exert real and meaningful control over their own lives. This growing sense of autonomy raises a number of dilemmas for health care practitioners and others who must balance an imperative to "protect" the health and safety of people with IDD with a sense that people with IDD are able to and should, where appropraite, make decisions that contribute to their sense of control of their own destiny. This is true when those decisions are contrary to what others believe are the healthy or safe choices, as it is for all of us.

In modern healthcare, practitioners, whose priority is to prevent disease and disability, must simultaneously elevate the status of people with disabilities. Asch, Gostin and Johnson (1) in "Respecting persons with disabilities and preventing disability: Is there a conflict?", puts it this way: "The field of public health faces a dilemma in the area of disability prevention. The mandate of public health has traditionally been read to embrace the prevention of disabilities. However, this mandate also includes a duty to enhance the well-being of persons with disabilities. Essential to this latter duty is increasing the respect of society for persons with disabilities" (1).

Discussions of ethics can take many forms. This chapter will attempt to approach the topic in three different stages: 1) a review of basic theories, including a short review of terminology and foundational understandings; 2) brief outlines of important historical events and 3) suggestions for practical consideration by active clinicians within the field of IDD in the early 21st century.

Ethical theories: "Ways" of "doing ethics"

Intellectual and developmental disability is a social construction that has, like all such constructs, evolved over time and across different societies. It is

currently defined by the American Association on Intellectual and Developmental Disabilities (AAIDD), as "a disability characterized by significant limitations in both intellectual functioning and adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18 years" (2).

Ethics is a process or method of thinking that is meant to encourage individuals and groups to act and think in manners that most improve human flourishing. There are many different methods that can be employed under the title of "ethics." The most common processes employed currently in the Western Cultures are grounded in the use of "principles," and is commonly referred to as "principlism." For example, "ethics" is defined by the Oxford English Dictionary (OED) as "a) (The title of) a study of or treatise on moral principles; b) The branch of knowledge or study dealing with moral principles; c) Moral principles; maxims, precepts, or observations concerning these" (3). Other systems of ethical theory focus not upon agreed-upon principles, but rather on the perception of rules that are considered fixed within the universe ("natural law"), intentions and habits ("virtue ethics"), measurable outcomes or consequences ("utilitariansism"), obligations stemming from relationships or duties ("deontology"), lessons learned from real or theorized experiences ("casuistry") or generally from stories ("narrative ethics"). In the following sections, each will be summarized very briefly, with references for further inquiry.

Principlism
In the early 21st Century, within the Western communities of care, the dominiant model of ethics within health care is principlism. The most commonly referenced text for this method is "Principles of biomedical ethics" (4). Here, four central principles are argued to be the foundational pillars for helping to determine best thinking or behaviors by individuals or groups struggling with ethical dilemnas: respect for autonomy, nonmalficence (avoiding harmful behaviors), beneficence (actively doing good), and justice (sharing goods or harms equally). Its dominance stems from at least three factors: 1) it was well-received as a corrective to the prior dominant system of "paternalism" (a system of ethics that preferentially defered decions to the prerogatives of physicians); 2) it is relatively easy to teach and explain, especially in relation to discreet examples of ethical challenge relating to one problem at one given moment; and 3) it is concordant with the current cultural moment in the history, which emphasizes individuals as happiest when their personal freedoms are least enfringed upon by dominanting external forces. Some critics of principlism have pointed out the limited importance it has given to issues that impact groups (i.e., justice) or that must be understood over epochs. Others have argued that it has neglected to account for individuals who are unable or unwilling to make decisions for themselves as autonomous individuals (e.g., children or individuals with intellectual impairments). A recent critique has suggested that one way forward would be to recast the definition of autonomy in more relational terms (5).

Natural law
Natural law is one of the oldest systems of ethical theory, dating from at least the early Roman period and strongly continued through to the present, espeically within specific religious traditions (e.g., Roman Catholicism) (6). Its foundational premise is that there are certain rules guiding human behavior that

can be discerned from observing the natural universe. The greatest strength of this system is that it can be articulated in a manner that has appeal across diverse cultures, continue across historical epochs, and respect different religious traditions. Many critics have argued that "natural laws" do not actually exist, but are projected upon natural phenomon by the proponents of this system. Although it is no longer the dominant paradigm for ethical theorists, there remain a large number of ethicists who partially or fully embrace its methods.

Virtue ethics

Virtue ethics is another contemporary ethical system that has both ancient roots and strong claims of universality:

> Probably every society has identified certain human characteristics as being especially praiseworthy and worth cultivating. . . . These traditions of virtues, in turn, have frequently given rise to systematic reflection on what it means to be virtuous (7)

There are traces of this thinking starting at least in Greek antiquity. Later, Roman culture also included a vision of the virtues, especially as articualted by the philosophical tradition of the Stoics and promoted by the great orator and public official, Cicero (106-43 BCE), that focused upon acting according to right reason. During the Christian era, the most influential promoters of virtues have been Augustine of Hippo (354-430) and Thomas Aquinas (c. 1225-74). Augustine built upon the Roman premise that there is one foundation for virtue. However, instead of using wisdom or reason, he places love of God at the foundation. In contrast, Aquinas introduces virtues as falling under the classification of habits: "Therefore human virtues are habits" (8). Contemporary virtue ethicists often specifically define themselves as not attempting to create systems that promote virtuous actions, but rather creating environments and expectations that help foster virtuous individuals:

> Renewed interest in virtue ethics arises from a dissatisfaction with the way we do ethics today. Most discussions about ethics today consider major controversial actions. . . . Virtue ethicists are different. We are not primarily interested in particular actions. We do not ask, 'Is this action right?' 'What are the circumstances around an action?' Or, 'What are the consequences of an action?' We are simply interested in persons. We believe that the real discussion of ethics is not the question 'What should I do' but 'Who should I become?' In fact, virtue ethicists expand that question into three key, related ones: 'Who am I?' 'Who ought I to become?' 'How am I to get there? (9)

Utilitarianism

Utilitarianism is an ethical system in which the right action is the one that promotes consequences with the greatest ratio of value to disvalue considered over a social unit. It also has ancient roots, but the modern form of classic utilitariansim has two philosphers most associated with its promotion: Jeremy Bentham (1748-1832) and John Stuart Mill (1806-1873). Bentham's promotion of this ethical system was in large part a reaction to natural law theories (10). He is considered the 'father" of modern utilitiarnism and set forth many of the current foundational axioms. For example in "A fragment on government" he

proposes that "it is the greatest happiness of the greatest number that is the measure of right and wrong" (10). Mill's position developed from Bentham (Mill's father was Bentham's secretary) and was connected to his desire to free sciences (including ethics) from biases, and therefore he promoted more quantifiable methodologies (i.e., falsifiability as a key test to the scientific process). This approach values only the outcomes or "consequenses" of actions, and not the motivations or intentions of the actors, which is why it is considered a form of "consequentialism" and stands in stark contrast with virtue ethics.

The most famous (or infamous, depending on one's perspective) current proponent of utilitarianism is Peter Singer (born 1946). His view is that personhood is determined by ability to have preferences, and all newborn children do not have that capacity (in contrast to newborns of other species) and therefore do not qualify as persons. In the context of this view, it would be permissible to actively euthanise infants who have conditions that would increase suffering (of the child, parents, or family). Further, Singer argues that individuals who do not have the capacity to ever have preferences would never become persons and therefore would always be candidates for euthanasia (11).

Deontology

The ethical theory that is most often specifically contrasted to utilitarianism is deontology. This school of ethical theory argues that the morality of actions is based upon duties. Its greatest proponant was Immanual Kant (1724-1804), who famously promoted a categorical imperative: "Act only according to the maxim whereby you can, at the same time, will that it should become a universal law" (12). His formulation has been compared (positively, in most cases) to the "Golden rule" often stated as "Do unto others as you would have them do unto you." This system of ethics has therefore ancient roots as well as many contemporary proponents: for one example, see Edward Pellegrino's "The Virtuous Physician" (13). The enduring strength and universality of this system is that it ultimately is simple to understand as well as being tied to relationships (unlike its foil, utilitarianism). Critics of this school have pointed out that deontology does not clearly help with ethical dilemmas in which there are two competing duties on the actors.

Casuistry

Unlike the prior ethical systems, "casuistry" is a system defined not by theoretical maxims or priorities, but rather the methods of trying to find the best moral solutions to an ethical problem. Western forms of this method existed at least by the time of Aristotle (384-322 BCE). It has been popular at times of rapid change, and reached its peak in popularity in the 16th to 17th Centuries, during the time of New World exploration, which brought many new challenges to the attention of ethicists. However, after this period, it began to decline, due to harsh criticisms [most famously by Blaise Pascle (1623-62)] of its misuse (i.e., to allow misbehaviors). Casuistry and its processes are present not only in biomedical ethics, but also in law and some forms of governmental deliberations. When a person or group faces a situation with choices that have contested or unclear outcomes, the ethicist attempts to find a prior experience (or "case") to compare with the current dilemma. This prior case (or cases) are then matched, and after their similarities and differences are taken into account, they are used to guide actions of the current actors. Casuistry is not a system in opposition to other forms of ethical thinking, as much as it is a supplementary

system about the ways to make the theoritical frameworks useful in practical deliberations. Jonsen and Toulmin in "The abuse of casuistry", revived its stature for the 20th and early 21st Century ethical debates (14). Like the prior period of influence, this text was important because many recognized that it appeared just at a time when technological advances were rapidly outpacing the systems and theories meant to help individuals decide the best ways to use the new technologies.

Narrative ethics

Like casuistry, "Narrative Ethics" is a term that refers to a process of how to apply theories to practice vs. the theories themselves. Generally, it is a method that uses stories of individuals or groups to prompt ethical reflection, both for individuals and groups. It is not as formalized an approach as casuistry, but shares with it the idea that individuals who are faced with ethical dilemmas can be guided by the exeperiences of others who have faced similar difficult situations. It is often associated with virtue ethics, due to their shared emphasis on the process of transformation of individuals as ethical persons, but it is not solely used for that purpose. Telling stories as a method of teaching moral thinking and action is as old a process as civilization, but the formal field that embraces the formal title of "narrative ethics" is relatively new (15).

Important recent history

In 1883, Francis Galton (1822-1911) coined the term "eugenics" and promoted its adoptation as general public policy. There were at least two forms of eugenics: positive and negative. Initially, 'negative eugenics', which promotes the "removal" of "undesired genitic material" predominated. In 1907 the first US state, Indiana, passed the first compulsary sterilization law, but it was seen as legally questionable. Therefore, a team of "experts" in eugenics, based at Cold Spring Harbor Laboratory and lead by Harry Laughlin, created a model state law that was first enacted by the state of Virginia in 1924 (16). This law mandated the sterilization of people with IDD. In order to test the constitutionality of this statute, the Virginia State Colony for Epileptics and Feebleminded [headed at the time of the US Supreme Court Ruling by Dr Bell, whose name is a permanent part of the case designation (17)], filed a petition to have Carrie Buck sterilized. Ms Buck was claimed to have an intellectual disability, along with her mother and daughter—a claim later discredited. Eventually in 1927, the US Supreme Court ruled in favor of the institution, a decision that has not been formally overturned, and Ms Buck was sterilized (16). In the ruling, US Supreme Court Justice Oliver Wendal Holmes, Jr famously opined:

> We have seen more than once that the public welfare may call upon the best citizens for their lives. It would be strange if it could not call upon those who already sap the strength of the State for these lesser sacrifices, often not felt to be such by those concerned, to prevent our being swamped with incompetence. It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind. . . . Three generations of imbeciles are enough (16,17)

The result of this ruling was that compulsory sterilization became commonplace across many states, with thousands sterilized against their will, with over 1,000 in Virginia alone (16,18).

Willowbrook
In 1947, the New York State Department of Mental Hygiene opened the Willowbrook State School on Staten Island against the will of local residents who fought its opening. It was initally opened as a hospital during WWII. It was designed for a population of 4,000, but it eventually held 6,000 children. Conditions were so bad that in 1965, when Senetor Robert Kennedy toured, he stated that the children were "living in filth and dirt, their clothing in rags, in rooms less comfortable and cheerful than the cages in which we put animals in a zoo" (19). Because of these conditions, hepititis infections were common. Researchers Saul Krugman (1911-1995) and Robert W McCollum (1925-2010) directed a study (1956-72) to examine the natural history of hepititis in this population and to test treatments for hepatitis. As part of these studies, the researchers purposely infected the children with hepititis (this included feeding new students the stool samples of children already known to have the disease). None of the children or their families were given complete information about this protocol and appropriate consent was not obtained. Eventually, when full disclosure was made about the study, it was terminated. After a lengthy battle and many investigative reports by news media, the school was finally slated to be closed in 1975 by the Willowbrook Consent Decree, although the last children did not actually leave until 1987. With the movement of children out of this institution, many were found not to have intellectual disabilities, but rather had been incorrectly diagnosed and labeled (20).

Baby Doe regulations
In 1982, in Bloomington, Indiana, a child was born with Down Syndrome and esophageal atresia. At that time, this congenital anomaly was routinely successfully treated with surgery. However, the family chose not to pursue treatment because the child had Down syndrome and the child died. When news of the child's death became public, the Surgen General, C Everret Koop (1916-2013), a pediatric surgeon who had himself performed the successful surgery many times, spoke out strongly against the decision of the family and treating doctors. Soon afterwards, in 1983, a child legally named "Baby Jane Doe" was born in New York with myelodysplasia [again, a condition that was usually treated successfully with surgery] that her parents decided not to repair. Her parents were brought to court by the US Department of Health and Human Services. By 1984, Dr Koop eventually convinced the US Congress to pass an amendment to the laws governing child abuse to include the prohibition of withholding fluids, food, or medically appropriate treatment for children who had known disabilities. The law formally went into effect on 1 June 1985. Initially, telephone hot lines were set up across the country and large signs were posted in Neonatal Intensive Care Units to allow anyone to report potential abuse. However, the US Supreme court eventaully struck down the regulations in 1986. The long-term impact of the regulations was to increase the scrutiny of decisions made related to children with known impairments, especially related to interventions that are known to be beneficial.

Ashley
In 2006, a team from Seattle Children's Hospital published a report on "attenuating growth" of children with significant physical disabilities (21). They

reported performing a hysterectomy and bilateral mastectomy along with high-dose estrogen treatment on a girl with IDD. Their stated objectives were to prevent her growth, which they hypothesized would improve her care, minimize her discomfort, and increase the time she could remain in the home of her parents. They offered no data to support their hypotheses. They did submit their proposed interventions to the Seattle Ethics Committee, which approved their protocol. After the publication of their work, the parents of this child started their own blog and joined the doctors in promoting this protocol to other families (22). The Washington State Protection and Advocacy (now renamed Disability Rights Washington) filed suit against the hospital, and the hospital admitted that it had broken state law, which prohibits the sterilization of women with intellectual disability without their consent or a court order (23). This admission also included admissions that their Ethics Committee processes and legal review processes were flawed (e.g., they relied on a legal opinion by the parents' lawyer as their "court review"). Many individuals and organizations spoke out against the protocol. Critics noted its lack of scientific rigor (there remains no data to support the claims that the treatment achieves its stated goals, even if the goals were considered beneficial), its implicit misogyny (no similar protocol was developed for boys), its use of a medical treatment to address a societal problem (e.g., inadequate funding and other supports for families), and its complete disregard to the bodily dignity of the individuals impacted. Despite these legal admissions of significant error, the lack of any data supporting their claims of potential benefit, the tremendous outcry by multiple leaders of the feminist, bioethical, and the intellectual disability communities, some of the authors of the original paper continue to promote this protocol (24-26). The pediatric endocrinologist who wrote the original paper (Daniel F Gunther) committed suicide on September 30, 2007 (26).

Suggestions for practical consideration

Professionals and families who are confronted with ethical challenges related to individuals with IDD have a broad and deep history of experience from which they can learn. A few themes emerge that are of particular relavance at the start of the 21st Century:

- Some ethical systems can be especially problematic for individuals with IDD. This is either because they do not have the capacities that would allow them to fully engage in asserting their positions as individuals (e.g., principlism) or because they are targeted for negative treatment, including euthanasia (e.g., Peter Singer's form of utilitarianism) (11,16)
- There is a long and ongoing history of treating individuals with IDD poorly in research, clinical care, and public policy, and often these poor treatments are then used to justify further mistreatment (e.g., Willowbrook and Ashley) (16,20-26)
- If one is to track the long-term trends, however, there are many positive in the practice of ethics related to research, clinical care, and public policy concerning individuals with IDD. For example, the prior experiences of Buck v. Bell, that had lead to state laws prohibiting hysterectomies, which then were used to help expose the errors of the Seattle team in the Ashley case. However, there are still significant problems with the current state of affairs. Again to cite Ashley, the Seattle team, including the Ethics Committee, was completely unaware

of these laws and completely ignorant of the care and legal concerns of individuals with IDD (20-26)

- Researchers, clinicians, and policy shapers within the IDD field need therefore to step forward and engage with the procedures of ethics as currently managed in research, health care, and public policy. This includes participation on IRB committes, Ethics Committees, and governmental panels (26).

Conclusions

Significant abuses, in the name of science, have been visited on people with IDD for generations. The lessons of the past and the systems that have been put into place are playing a significant role in prevention of abuses while promoting best practices. Ethical principles can be helpful in guiding decisions conerning research and practice that take into consderation basic human rights and equity. Furthermore, treatments and approaches to supporting people with IDD must strike a delicate balance between what the healthcare practitioner or other caregiver may believe to be best for the person and what the person believes is best.

In The ethics of autism (27), Professor Deborah Barnbaum offers a one perspective on this situation: Any suggestion of re-making the world of an adult with autism - an adult with his own personality, beliefs, and preferences - is a failure to recognize him as his own person." Autism spectrum disorders are not something to be cured, per se, but are part of the wonderful diversity present in the great population of humanity. In such a context, people with autism—and indeed any IDD—should be supported in such a way that they are empowered to live out the lives in a manner that they believe allows them to uniquely flourish (27).

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