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Deciding Who May Choose:

The construction of Personhood During Ethical Decisions in a Biomedical Context

Laura Martini

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Professor Helmreich

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The concept of ethics is often discussed as if it is a universal entity that applies equally to all people in all situations. The very concept of ethics, however, is created and enforced by humans, and therefore is an entirely social construction that must be continually re-constructed and re-defined in order to apply to new situations. In this paper I will use the framework employed by Margaret Locke in examining role of brain death in the construction of personhood (2002), and apply it to the contrasting concepts of personhood drawn upon and created by families, ethics boards, biomedicine and courts as they make decisions about and for individuals with disabilities in the United States. In addition to published sources, I will draw on personal experience as well as interviews I conducted with psychologist Dr. Don Brunquell, director of the office of ethics at Children's Hospitals and Clinics of Minneapolis and St. Paul (hereafter referred to as Children's).

I am drawn to this topic by personal experience: my older sister, Sarah, has undergone more than a dozen surgeries to correct a host of physical problems she suffers due to a rare genetic disorder she has, called Rubinstein Taybi Syndrome. The first medical decision my parents made for Sarah was to allow her to undergo lifesaving open-heart surgery as a baby, which coincidentally took place at Children's. Since then they have faced both easy medical decisions, like whether to correct her ingrown toenails, and difficult ones, such as whether to have Sarah undergo a second open-heart surgery when she was nine. Among these surgeries only one, the hysterectomy she had in her mid-teens, has required consultation with an ethics committee. Although my parents have had little formal interaction with these committees, at every surgery and decision throughout my sister's twenty-five years they have grappled with ethical dilemmas, both small and

large, and have lived daily with the ramifications of their decisions. I personally find it interesting that the hospitals did not require an ethics committee consultation before any of her major surgeries, after which she spent a week or more in intensive care – such as the lifesaving ones to repair her heart, and later to straighten her spine from scoliosis – did not require ethics committee consultations, whereas the medically minor hysterectomy did require consultation. Part of this discrepancy may have stemmed from the fact that the hysterectomy was elective, whereas all other surgeries were done to correct a problem that was causing her pain or would have killed her. I would like to argue that the different ethical treatment of Sarah’s surgeries is much more complex, and serves to illuminate the basic assumptions of personhood within the United States. Through this paper I will explore the construction of this personhood within the context of American biomedicine.

The elemental concept of ethics influences all definitions of personhood in biomedical contexts. In anthropology, ethics is considered essential to all interactions between ethnographers and their interlocutors. The American Anthropological Association’s Code of Ethics “provides a framework, not an ironclad formula, for making decisions.” An important element of this framework is obtaining “informed consent”(Code of Ethics of the American Anthropological Association), a requirement that is problematic because informed consent is difficult to quantify. Although there are certainly instances where one can be assured that a person is or isn’t capable of consenting – be it to an anthropological interview or to surgery – there are also times when it is tricky, if not impossible, to determine one’s ability to give truly informed consent. It is at these boundaries that the very essence of personhood is illuminated.

It is important to note that despite its implied universality, ethics isn't ever socially, politically or culturally neutral. Ethics committees must take into account the personal beliefs of a person and their family, such as religion when giving guidance. Committees and courts are an attempt at the secularization of morality in that they serve members of all religious and ethnic backgrounds, and all stages of life. Although ethics committees strive for neutrality in their recommendations, a critical element of their consultation is their ability to balance an individual's beliefs with societal standards.

In order to grasp how ethics boards function, it is important to understand how they came to be. Before there were ethics boards, there were families and doctors in dialogue, with only the courts to mediate points of contention or ambiguity. It is easy to see how this system was problematic; drawing the legal system into in any matter is lengthy, expensive and involved, and moves the situation beyond the private sphere where the family has agency and into the public sphere. When Sarah was born in the early 1980s, the movement for ethics boards was also in its infancy. Medical advances in the second half of the 20th century meant that suddenly there were more decisions that could be, and there for needed to be made. Previously, babies with severe physical defects simply couldn't be saved, now there were surgeries and techniques that enabled them to live (Rapp 2000: 269). My parents have recounted to me many times that the open-heart surgery that saved Sara's life had only been developed during the decade before she was born. As a child, I had always thought that my family was extremely lucky that my sister was born during an era when doctors knew how to save her. I now realize that this was a mixed blessing, as the availability of lifesaving technologies forced my parents into the role of "moral pioneers" (ibid. 3) as they confronted life-and-death

decisions about Sarah. In an era of new medical technologies that necessitated an increasing number of medical decisions for parents and families of mentally retarded individuals, it became obvious that patients, their families and their doctors needed guidance in navigating their options.

At this point, all hospitals have ethics committees or “some other mechanism for resolving ethical dilemmas”, as mandated by the Joint Commission on Accreditation of Healthcare Organizations (Steinberg 2007: 7). In general, the importance of ethics in biomedical decisions has become much more mainstream since Sarah was born. “Most American medical schools teach medical ethics, and national board exams test candidates for their understanding of key ethical principles. And now, interactive sites on the Internet provide immediate instruction and counsel for vexing ethical dilemmas” (ibid.). The ethics committee at Children’s is composed of “20 people...- 6 physicians, 3 nurses, a social worker, 2 chaplains, 4 parent members (whose children have received services at Children's), an outside clergy person, an outside ethicist, an outside lawyer, an administration representative, [Dr. Brunnquell], and two emeritus members” (Brunnquell 2008). It is interesting to note that many of the committee members have no formal medical training.

This committee, as is legally required of all ethics committees, functions as a decision-affecting body, not a decision-making one. The committee at Children’s operates under the assumption that the family is the central decision-making unit, meaning that they only take on cases when their advice is sought. In these cases, the committee acts as a sounding board for doctors, patients and families who come to them for advice (Brunnquell 2008). In Sarah’s case, it was the gynecologist performing the

surgery who sought the counsel of the ethics board and presented Sarah's case on behalf of her and my parents.

Discussion of mentally retarded individuals in biomedical contexts illuminates many interesting aspects of societal assumptions about personhood. One major question that must be answered is whether, and to what extent, a person is capable of making medical decisions for themselves. In the United States adult persons are assumed to have autonomy unless they are deemed unable to make decisions for themselves. This concept is often referred to as self-determination. "A right of self-determination flows from the principle that persons are autonomous agents whose considered judgments deserve respect. The Catholic church, for example, has generally acknowledged the right of competent patients to refuse treatment even in cases where the refusal itself is not ethically justifiable" (Veatch 241). Not too long ago, mentally retarded individuals were thought to be incapable of any level of agency, and were often locked away in institutions. The pendulum has swung in the opposite direction, meaning that courts now view individuals with mental retardation as deserving of autonomy when it is possible to accord them these rights (Simon 2002). The question then becomes where to draw the line in determining the extent of their competency to make informed decisions, and in which circumstances

Biomedicine and law have looked to IQ in order to help answer this question. This model assumes a level of agency that can be taken away only if a person's IQ is deemed too low. Although this measurement, when applied to biomedical decisions, has the unfortunate history of being associated with eugenic interests (Davis 2006: 8), this numerical measurement is legally defensible and easy to apply uniformly. This method is

problematic, however, in that “It does not describe the level and nature of the person’s experience and functioning in aspects of community life” (Simon 2002: 147). This definition also assumes that IQ tests will accurately measure the intelligence of a mentally retarded person. When Sarah underwent the IQ tests needed to qualify for government assistance, she was so distrustful of the person administering the test that she refused to talk, resulting in what I can only assume to be an IQ score that underestimates her abilities. In some respects, my parents were fortunate that they never had to deal with the ethical dilemma of whether Sarah is capable of giving her informed consent; it has always been clear that, regardless of what the IQ tests might say, she does not have the mental ability needed to project into the future in order to understand the consequences of her choices, a critical element of informed consent.

It is interesting to note that even though the measurement of IQ is relatively static over time, the ways in which society chooses to employ and interpret this measure is not. “Parental experiences of childhood impairment have been shaped, since the 1960s, by changes in social attitudes and policy, including the independent living movement, ... the Americans with Disabilities Act, and programs for early intervention (Public Law 99-457) and inclusive Education Act (IDEA)” (Casper and Laine 2005: 183). These movements embody the evolution in attitudes about mentally retarded persons throughout the past century, from isolation to integration. Ethics committees must act within this ever-changing societal construction of personhood for the mentally retarded. Medical advances and societal acceptance of the mentally retarded have co-evolved; as more medically-treated, mentally retarded individuals have survived, they have been able to lead (and society has created institutions which allow them to lead) increasingly

integrated lives with the rest of society. In Sarah's case, she has lived in a group home since she was nineteen. She currently attends a day program through which she has a job putting food in vending machines, and enjoys weekly visits with my parents. Although Sarah is happy and, arguably, a productive member of society, when my parents were making the first big medical decision when Sarah was a baby, there was no way for them or doctors to know what the future would hold for her. There were no guarantees that necessary programs would be in place for Sarah when she grew up, allowing her to be an integrated member of society. In fact, had Sarah lived in a district without the infrastructure like the group home she lives in and the day program she attends, my parents would have had few options other than to care for her indefinitely or place her in existing care facilities like nursing homes, which are ill-equipped to deal with the needs of young people (Santora 2008). Doctors, families, courts and ethics committees all operate within a framework of unknowns. These institutions all are bound to, but simultaneously help to create, the landscape in which they are making decisions.

When patients and their family members are making medical decisions, there is a certain framework of norms, past precedents, and legal standards to which they are confined. This framework "acknowledges the guardian's central role, but at the same time sets limits" (Veatch 1986:251). It is often necessary for decision-makers to justify their decisions. There are varying opinions on what justifications are acceptable, a criterion that depends on who is making the decision. I will return to this discussion later.

Another factor that influences the decision-making process is the very language with which this discussion takes place. Just as Rapp describes the experience of pregnant women who feel restricted by the medical vocabulary that they must use in order to

convey their wishes (2002: 5), the decision-makers for mentally retarded individuals can feel limited by the very way the question is framed. I would like to employ Rapp's framework of distinguishing choices from decisions: choices are made from among any number of possibilities whereas decisions are made from a very limited set of options (2002). For example, when it comes to schooling, parents must make a decision from a limited set of options: "Parents have discretion to choose among competing school systems, but they cannot go too far. In other words, they can choose military or experimental or parochial schools, but they cannot choose no schooling at all" (Veatch 1985: 246). When my parents confronted their first ethical dilemma with Sarah, her open-heart surgery, my parents had to decide between lifesaving surgery and a future filled with painful follow-up procedures or no surgery and certain death. Although their informed consent was required in the form of a signature, my parents have emphasized that they are not entirely sure they had any other options. The cardiologist and surgeon never specifically discussed with them whether they wanted the surgery done – weighing the ethical complexities of the option not to do it, and let Sarah die. As first-time parents, they were dealing with a complex mixture of grief, anxiety, and future unknowns. The momentum of the Minnesota medical environment in 1982 was to do whatever heroics could be done medically. The longer-term impacts to families and the impact of the family's decision might have on the larger society weren't explored, or even mentioned. At the time, the ethics committee at Children's had just been formed (Brunnquell 2008), indicating that my parents were truly moral pioneers. Although families of mentally retarded individuals are required to give their informed consent, they must give this consent within a very narrow range of options.

By enacting the decision-making process, families, hospitals, review boards and courts each construct their own vision of personhood. There is nothing inherent about someone that one can point to as the essential element of personhood that signifies the cutoff point between those who are and aren't capable of making decisions about themselves. Personhood is a social construction, "a process conferred, attenuated, contested, and withheld by the collective. It does not reside in the physical or cognitive attributes of individuals" (Kaufman and Morgan 2005: 321). The four decision-affecting bodies I am examining in this paper all have different definitions for an individual: families see a person within the context of the needs of the parents and siblings of a mentally retarded person, whereas ethics boards see the individual as a patient with human rights to protect; courts focus on the person as having legal rights they must enforce, whereas biomedicine emphasizes a patient's biological needs. At the heart of the issue is the construction of what an individual is and what treatment they ought to be accorded. The word 'individual' is frequently used, but has been interpreted differently by various institutions and throughout in history.

One of the reasons that mentally retarded individuals raise difficult questions in American biomedicine can be explained by the fact that the brain lies at the heart of a person's identity (Locke 2002: 95). The brain is often synecdochic for an individual, and thought of as the site in which a person is internally constructed. Without a fully-functioning brain, it is impossible for one to have an "individual interest" (ibid. 7). Although it's impossible for mentally retarded individuals to enact many elements of personhood, especially those needed for agency in a biomedical context, the universal concept of human rights assures respect towards all individuals (Kopelman 1984: 19).

Regardless of a person's ability to make a decision, they are guaranteed their fundamental rights (Jordan 1985: 100). I will now explore the reasoning behind the rights given to mentally retarded persons.

Throughout American history, a person has been defined as an individual deserving of "inalienable" natural and human rights (Kopelman and Moskop 1984: 21) . In a medical context, this is interpreted as an entity who has a "best interest" which is supposedly "self evident" to a "rational person". In the United States law, an individual is considered self-contained until a situation like mental retardation removes their agency and places it under the control of a bigger body like a family or the courts. Throughout history, the rhetoric of human needs has evolved into that of human rights. A right that is undoubtedly problematic in the context of persons with disabilities is that of "lifelong good health [which] is clearly included in these expectations" (Locke 2002: 33). This sentiment helps to illuminate why Sarah's painful and involved lifesaving surgeries were not questioned, whereas the hysterectomy that did not directly assure her of better health was questioned. Within this system of rights, mentally retarded individuals are accorded little, if any, ability to make their own decisions. "If there are rights here, they will for the most part be rights to a certain kind of paternalistic protection" (Kopelman and Moskop 1984; 10). While the American biomedical system operates within the framework of a person as an autonomous entity – though guardians of adults with mental retardation legally make these decisions on behalf of the individual – it is important to note that such autonomy is not granted in all societies (Locke 2002). For example, in countries such as China and Japan where "the 'best interest of the patient' is not seen from the view of the patient, but of the healthcare team and all the family members" (Steinberg 2007: 261).

This emphasis on communal rights has been detrimental to the disabled communities in those countries, meaning that “the disabled have had to struggle to be heard” (Locke 2002: 174).

The American framework of autonomous individuals deserving of rights necessitates enacting the idea of individual interests and leads to the concept of informed consent. “This means receiving adequate information about the risks, having adequate mental capacity to process that information, and finally, not being coerced or unduly pressured” (Steinberg 2007:211). This concept of coercion is interesting; what may count as coercion in the United States (a family pressuring one of their members) may be expected behavior in a different country, like Japan. In addition, “The quality of [one’s] informed consent or refusal hinges on the quality of provided information as well as [one’s] ability to assimilate this information” (ibid.: 213). In a litigious society like ours, informed consent has taken on a legal meaning (Locke 2002:173). Informed consent must be enacted by filling out paperwork and giving one’s legally-binding signature.

This rhetoric – of the United States being a confederacy of autonomous individuals – while oft-repeated and employed, obscures the social reality of persons as members of families and society. “In many families the emphasis on individual autonomy and control is culturally inappropriate. Thus, family members and community representatives often are involved in medical decisions” (Steinberg 2007: 257). This family membership entails certain obligations and these embedded social relationships frequently affect what is considered to be a person’s “best interest”. By virtue of being a member of a family, the decisions about a person will be affected, for better or worse. “Some argue that being a family member, by its very nature, puts one in a coerced

position” (ibid.: 211), and families are important for constructing the identities of their members: “the family still remains an indispensable substrate for the ongoing construction of the identity of all its members” (Caron 2007: 216). Although families help to create a person, it is a matter of contention as to whether it is acceptable to take into account the needs of the other members of the family when deciding a person’s best interest. I will return to this topic later.

Much discussion about bioethics rests on the assumption that the actor is rational, but this definition is problematic because there is no such thing as a set of decisions that would be made the same by every rational person (Kopelman 1984: 19). “Rational people disagree all the time because they operate on the basis of different premises, knowledge, and values. For some doctors, a concern with patient rationality and autonomy is paramount. But that concern may interfere with their ability to understand and relieve the desperation that underlies the request for death” (Steinberg 2007: 248). Once one begins to examine the gray areas of biomedicine in which there is no simple answer to what course of treatment is best, it becomes clear that the framework in which Americans operate is not so self-evident. The debate surrounding medical treatment for mentally retarded persons illuminates how this framework undergirds the American biomedical system, but does little to resolve the questions that this system inevitably raises. On some level, “best interest” can be interpreted as what is best for society; people are supposed to control themselves without outside intervention. This expectation is generally assumed, and is only made explicit when an individual is deemed not capable of making decisions for themselves. The fact that there is no such thing as objective rationality means that

humans must construct a system to make decisions for those who cannot make them themselves.

Ideally a person is able to comprehend a medical situation and act on their own best interest in order to make medical decisions. In lieu of that, another body must step in and make decisions on their behalf. Despite the differences in the way they define personhood, all four bodies are in agreement that the family should be the first to make decisions when a person is deemed incapable. Each institution fills a role, and none of them would be sufficient in every situation. “Each is inadequate because the very nature of the institutions themselves renders them unable to reach a decision which is essentially moral and each of these institutions is, by its nature, public, objective, and scientific or democratic” (Jordan 1985: 106).

In the United States the nuclear unit, consisting of parents and siblings, is the most often used definition of family. Families are considered the base unit for decision-making, even when ethics boards and courts get involved; while a family’s decision may be questioned, their right to make the decision rarely is (Veatch 1985: 248). Although courts may eventually overrule a family’s wishes, the prevailing mindset is that families are entitled to act on behalf of a mentally retarded individual. Brunquell explains that at Children’s “The ethics consultation is not the actual decision-maker- that role remains with the parents with the input from the health care team; the ethics committee can advise but not command” (2008). This mindset is universal. The role of ethics committees in the United States is to provide a support system and aid parents and hospital staff as they are facing difficult medical decisions (Greer 2004, Steinberg 2004, Laura and Ashman 1985). An important element of this consultation process is to apply some level of

uniformity to how everyone involved interprets the situation – “to help families and staff members understand the information in the same way” (Greer 2004). Because ethics committees must encompass a wide range of beliefs and take into account the cultural, religious and historical beliefs of a patient and their family, their construction of personhood is the most situational of the institutions I am examining in this paper.

There is a certain set of choices that families are allowed, as well as a limited set of reasons on which they are allowed to base these decisions; where a patient would have gotten to choose from the entire alphabet, other decision makers only have the options of A, B or C. There is some disagreement between those who feel that a family’s needs should be taken into account, and those who believe that it is only right to consider the child’s interests. Although families are allowed to make decisions when their members cannot, they are not given the same set of choices as those individuals would have been allowed if making the decision themselves. Veatch contends that “While the individual autonomy of the competent patient is unlimited in medical choices, familial autonomy cannot be” (1985: 246). As I mentioned previously, when my parents consented to the first of many lifesaving surgeries for Sarah, they were more restricted in their options than Sarah would likely have been were she to have been capable of giving the consent herself. While Sarah could have refused the surgery, my parents are not entirely sure that they would have been allowed that option.

Others take a more nuanced approach than Veatch with regard to the treatment of persons with mental retardation. Where Veatch thinks that taking the needs of others into account is morally reprehensible in all but the rarest of circumstances, others advocate for a balance. One example of this reasoning is as follows:

“the final reality of decision-making is tied to a complex balancing test of weighing economic costs of nonmaintenance against the social benefits of maintenance. Stated another way, decisions of this scope and dimension are reached by balancing the gravity of the economic harm that will accrue in a particular case of maintenance against the utility for the social good that will occur for non maintenance” (Laura and Ashman 1985: 130).

I think that this framework is overly simplistic; I merely offer it to contrast with Veatch’s approach. Laura and Ashman also offer another framework for decision-making, that giving by vitalists. Their position is that “such decisions should be made on medical grounds alone, that ‘quality of life’ considerations are irrelevant. This position is called ‘vitalism’. By contrast, anti-vitalists think that life need not be prolonged when prolonging it is not in the infant’s best interest, although they may differ widely on what that is” (1985: 102). This framework is closer to that laid out by Veatch, in that it only takes the patient’s rights into account. However, this latter construction does allow for the fact that a person’s best interest may be affected by those around him or her. There is a dissonance between the actuality of the importance of a family in constructing a person’s identity and self-interest, and the philosophical discussion of a family’s proper role.

It is interesting to think that one might be able to de-couple an individual’s rights from a family’s rights in this manner. Does it make sense to assess a person within a vacuum, when their very identity is formed by their surroundings? If morality is dependent on what societal groups the individual belongs to (Jordan 1985: 56) then why is it not relevant to take the needs of others into consideration? If the child will end up causing a divorce or financial hardship for a family and thus cause harm to their siblings

and parents, why is that not a legitimate factor to consider? Why is it that logically irrational choices, such as refusing blood transfusions based on religious beliefs, are allowed, but arguably rational decisions – such as refusing lifesaving treatment because a child would lead a life filled with expensive but life-saving (not to mention painful) surgery – are not allowed? This limited set of acceptable reasons is not universal. For example, in China, decisions like whether to remove life support can be based on economic rather than ethical considerations (Steinberg 2007: 260).

In contrast to family, where all decisions will inherently be made within the framework within an individualized set of beliefs, the state's role is that of impartiality; they are charged with implementing a secular morality. The courts are “unbiased arbiters whose impartial deliberations issue in decisions which most closely approximate justice” (Jordan 1985: x). In some respect, the courts have the final say in the decision-making process, by virtue of being able to appoint a legal guardian for any person deemed incapable of making decisions for themselves. In actuality, this power is only enacted in the rare situations where doctors, hospitals and families escalate particularly difficult decisions to that level.

Although the courts strive to be impartial, in truth they are subject to their own biases. These biases change over time, which is good; since the courts are socially constructed to begin with: it would be a terrible thing if they didn't evolve over time along with the societal norms they are enforcing. As society recognizes the importance of rights for mentally retarded individuals, institutions like courts need to be reshaped in order to “accord them their rights” (Kopelman and Moskop 1984: 57). It is very rare that courts need to become involved in cases pertaining to medical decisions for mentally

retarded individuals, but they do have the ability to intervene. “Under the doctrine of *parens patriae*, the state has a right, indeed, a duty to protect children... [but] it has a serious burden of justification before abridging parental autonomy by substituting its judgment for that of the parents” (Veatch 1985: 248). If no family opinion is available, a court may be called in to act on a patient’s behalf (Steinbberg 2007: 197). The court’s role is mainly that of defining norms: the courts are involved in only a small fraction of medical decisions for mentally retarded persons, but those cases which they do hear become the basis for decisions made within families. Court decisions provide a way to formalize societal beliefs.

The final institution that I would like to discuss is the doctors themselves. Through their lens, a mentally retarded person is first and foremost a patient. Doctors are trained to provide medical counsel, but the related ethical counsel has been delegated to ethics committees. Doctors are caregivers, not moral decision-makers (Jordan 1985: 87); in lieu of having a patient’s family make decisions, they will often defer to another body within the hospital, or appeal to the courts in order to have a legal guardian instated (Steiberg 2007: 210). The modus operandi in the past has been to save whomever technology could allow to live. There’s some evidence that this is changing, and that hospitals are understanding that its their duty to let some patients die. Brunnquell explains that there are some decisions when the committee advocates for cessation of “aggressive life sustaining treatment for [a] child that is very invasive and painful” (2008).

These definitions of personhood organize and anchor the way in which families and individuals ultimately make biomedical decisions. Each institution fills a role, and none of them would be sufficient in every situation. Every line of thought brings new ideas to the discussion, and helps to develop the constantly evolving concept of personhood. The concept of self-determination for individuals with mental retardation is in flux; in the past half century it has gone from a far too few rights to perhaps too many: Simon feels that mentally retarded individuals like her sister are given the opportunity for agency that is beyond the scope of their capability, which ultimately ends up conflicting with their best interest (2002: 180). She explains that “We are in an age of new rules, and no one quite knows how to use them” (284). The rules, power relationships and societal norms Simon invokes are formalized in the institutions I have discussed in this paper. In these institutions, one must draw the line between two distinct categories (e.g. able to give consent or not able to give consent) even if those lines don’t naturally exist. By looking at who is drawing the line, and how they are drawing it, one can define the notion of personhood that these institutions are constructing.

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