

## CHALLENGING INCOMPETENCE

### THE MEANING OF SELF-DETERMINATION

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The foundation of self-determination for individuals with disabilities in the United States rests on a set of principles deeply rooted in equality and both civil and human rights. Self-determination starts with the basic ideas of freedom to design a life plan, authority to control some targeted amount of resources, support that is organized in highly individual ways and responsibility for both the wise use of public dollars and the civic obligation to contribute to and be part of one's community. Standing in apparent contrast to this movement for equality is the legal and ethical basis for guardianship. The formal stripping away of rights guaranteed by the Constitution and the Bill of Rights presents a formidable obstacle to the exercise of self-determination at least as it has been articulated since the early 1990s. (Nerney, Crowley, 1993; Nerney & Shumway, 1996)

The importance of defining the meaning of self-determination and challenging the prejudice against individuals labeled "incompetent" require us to examine the imposition of guardianship. Guardianship remains as one of the major obstacles to addressing a new and more dangerous vulnerability that people with disabilities are now experiencing. "Incompetence" and chronic disability have become the targets for a new eugenics movement that essentially aims to remove most protections for this population that were previously guaranteed by law, tradition, religion or common decency. Court sanctioned classifications of "incompetence" reinforce the already existing societal prejudice against those with cognitive disabilities. It is important to note that guardianship in and of itself is not the only or sometimes the major impediment to the exercise of self-determination. However, the imposition of guardianship reinforces the stigma attached to our society's view of "incompetence". Addressing this issue is part of a coordinated campaign that needs to be mounted to speak to the newly energized eugenics movement that has targeted individuals with intellectual disabilities. Explicating the "meaning" of self-determination may begin to help us develop tools to overcome some of the unwarranted assumptions that lie behind and beneath these newly animated eugenic arguments.

This essay constitutes an opening dialogue to assist in re-evaluating both the foundation for traditional notions of guardianship as well as the implications of a legal process that frequently leaves individuals with disabilities on the margins of society bereft of normal freedoms that all Americans take for granted. This is not to say that many family members don't seek guardianship as a legitimate way to protect their

sons and daughters, mothers and fathers even, from the vagaries of the present system. Very few alternatives have been offered to them. For caring family members, guardianship may seem like the only way loved ones can be protected. Further exacerbating this problem is the fact that only those with "legal" rights are able to access information and gain standing with representatives of both the public and private human service sectors. In fact, though, the imposition of the dreaded label "incompetent" only adds to the vulnerability of individuals with disabilities.

There is, however, another discussion that needs to take place regarding the importance of reforming guardianship statutes in this country. It has to do with the social, cultural, ethical as well as the legal implications of deeming someone "incompetent" in this society and the resultant loss of status and value for the person with a disability.

In the early 1990s, as we began articulating the meaning of self-determination in the first demonstration project in Southwestern New Hampshire, one of the persons involved with this demonstration had to be admitted to the local hospital for surgery. This was a woman with significant cognitive and physical disabilities. Before she even got to a room in the hospital, those accompanying her were presented with a form that "needed" to be signed. An inquiry was made as to the whereabouts of her guardian. This was not an admission form. It was a form that appeared to recommend a do-not-resuscitate order be placed in her record.

We were informed that this was "patient self-determination". We were appalled. Over the next few days as the hospital administrators kept up their requests, a flow of direct support staff, case managers, agency administrators, and friends began a steady stream to her bedside. Someone remained with her 24 hours a day. The room began to fill with flowers and balloons. Soon the hospital desisted. They had come to the conclusion that this person was not a candidate for a do-not-resuscitate order but, rather, some sort of VIP.

What happened in that hospital setting is replicated every day throughout the country. It is especially dangerous for individuals with cognitive disabilities. It is sometimes even more dangerous for those with guardians especially guardians who do not see them as equal citizens with equal worth.

We were confronted that day with a version of self-determination that contrasted starkly with our vision of self-determination. While some aspects of patient self-determination overlap with our vision of self-determination, they are fundamentally different in their history and their foundation. The differences are important as we begin to wrestle with

the meaning of guardianship (as well of our entire human service system) because contemporary understandings of guardianship have been shaped by a history that posits "incompetence" as a barrier to the exercise of autonomy or self-determination. Traditional notions of guardianship are rooted in this history especially as it has unfolded from the ethical and legal community in the second half of the twentieth century. Our definition of self-determination requires a reassessment of guardianship as well as a reassessment of traditional service and funding arrangements.

The imposition of guardianship is a civil process that removes the essential liberties guaranteed by our Constitution and Bill of Rights for vulnerable adults who are deemed "incompetent". For individuals with cognitive disabilities it is unfortunately a commonplace, even a routine experience.

It must be said, however, that many individuals with cognitive disabilities are vulnerable, subject to exploitation and sometimes lack adequate understanding in order to make informed decisions and choices. We can afford neither to underestimate the reality of disability nor to ignore the limitations it may very well impose.

Therein lies the fundamental tension at the root of the movement toward self-determination for these individuals. If self-determination posits freedom as a primary principle then this has to be meaningful for all individuals with disabilities no matter how significant that disability may be. How do we address this seemingly contradictory set of principles: protecting persons from harm and exploitation and insuring basic freedoms. The answer cannot be a simple abolition of guardianship that abandons vulnerable individuals. Nor can we any longer ignore the lasting, stigmatizing effects of the stripping away of basic freedoms. Besides the important liberty issues presented by the imposition of guardianship there is an equally important issue that comes with a declaration of "incompetence". Those who are guardians or who support this transaction need to know the implications for acquiescing to the ethical and legal ramifications of incompetence.

In accepting the legal and ethical definition of incompetence we may lose sight of the most serious and sustained attack on people with chronic disabilities in the latter half of the twentieth century. Once we become aware of these implications we may risk becoming complicit in sustaining ideas that we do not in fact support.

## Background

The imposition of guardianship in our culture results from a finding of incompetence. Incompetence, a mostly legal term with broad social implications, is almost always a situational assessment. It is predicated on

the notion that a person cannot make an informed decision about a particular task, event or activity. A person is deemed to not be able to make a particular decision about a medical procedure, e.g.; or it is determined that a person cannot make any rational decisions. It is an up or down proposition. The first may result in partial guardianship and the second in plenary or full guardianship.

There are two generally accepted theories of guardianship: "substituted judgment" and "best interest" decision making. Substituted judgment is usually reserved in ethical theory at least for individuals who once could make decisions. They may, e.g., have advance directives in the health care arena or the guardian is required to ascertain what the person might have chosen had they been "competent". Best interest decision making is usually reserved for children and those who are considered not to ever have had the competence to make decisions. Individuals with life long cognitive disabilities more frequently end up in the second category in most contemporary ethical theory. This distinction, however, matters very little in practice since most guardians receive very little training on their obligations even under substituted judgment.

## COMPETING DEFINITIONS OF AUTONOMY OR SELF-DETERMINATION

Patient self-determination rests on a legal and bioethical theory of autonomy. The person who is competent is his or her own moral agent. Only the person can determine what is best or what constitutes good choices or well being. This theory of autonomy as self-determination rests on the notion that an individual is competent and can therefore determine what constitutes a good decision. There is some debate about just how far this notion of autonomy can be taken, but, aside from involuntarily affecting others, there is general agreement that it remains an ideal organizing principle for many facets of life.

There is of course a lot to be said for understanding the importance of autonomy. It has been a useful tool in addressing the historic paternalism of the medical profession. It is at the root of the political gains that women and minority groups have made in the past century when it is understood in its original political context. It is best known today in the field of medicine and health policy. That said, it rests for many ethicists and legal experts on a foundation that has proved to be very dangerous for individuals with disabilities if the political and social context is missing. Autonomy, then, in this discussion, represents the use that historical interpretations of "reason" and "reasoning" has served throughout Western philosophy dating back to Plato and Aristotle. It has been used as a pretext to elevate one group, usually males, from sharing political equality with others, usually women and those occupying lower rungs on the social scale including slaves.

The dominant school of contemporary ethical theory holds that lack of autonomy or the ability to self-direct creates a second class of individuals in this society, a class intellectually unable to benefit from the freedoms guaranteed to all other citizens. The implications have proved to be very costly indeed. Conversely, autonomy rooted in equality, democratic theory and the political and civic expression of freedom takes us down another, more positive, road.

The application of autonomy as an isolated principle in the field of medical treatment and human experimentation is instructive. Where better to understand this issue than in the realm of life and death decision making.

### THE DOWNWARD SPIRAL FROM NUREMBERG

In 1947 nine American judges sat at Nuremberg to judge the Nazi "medical" experiments. They heard 133 days of horrific testimony concerning experiments carried out by some of Germany's leading scientists and doctors. The world is still repulsed by these lethal and degrading experiments. The judges at Nuremberg articulated ten standards that were necessary for a medical experiment to be considered legal or ethical. The first one had to do with the principle of informed consent: voluntary consent was based on the principle of self-determination and the notion of autonomy. Experiments could not be carried out without informed consent.

While this may not have been the first articulation of this principle of self-determination, it was and remains the most famous. It seems especially flawed in one respect. The medical experiments that were the subject of this trial were so barbaric that no coherent ethical or legal theory could ever sanction the experiments themselves let alone provide support for anyone to consent to them. Moreover, the judges at Nuremberg never adequately addressed the murder of well over 200,000 individuals with disabilities and the sterilization of over 400,000 German citizens. Only recently have historians begun to address the ambiguity of the Nuremberg prosecutors over this issue and the failure to bring so many major figures to trial. (Kuhl, Stefan, 1994) This may be because the American experience in the first half of the twentieth century was marked by the banishment of tens of thousands of individuals with disabilities to public institutions through state statutes that exceeded in viciousness the Jim Crow segregation statutes of the South. In 1942 the eminent American psychiatrist Foster Kennedy called for initiating in the United States the same protocol that Hitler used to begin the extermination of people with disabilities in Germany. (Foster Kennedy, 1942) His words provided the turning point in the debate over the value of persons with disabilities that once again has surfaced publicly long after

the Second World War ended. Foster Kennedy suggested that it was morally acceptable to "kill with kindness". Kennedy's assessment of the value of individuals with disabilities represents the nadir of the first eugenics movement in the twentieth century in this country. It also represents the "new" reasoning that has come to dominate the field of bioethics today and lies at the heart of a full blown second eugenics movement. It remains unclear whether the Nuremberg Justices were likely to see the killing of individuals with disabilities as a crime against humanity.

That said, the ideal of patient or subject self-determination became firmly rooted in the then nascent and now fully developed field of bioethics. The troubling aspects of this isolationist version of self-determination become more apparent when we address the issue of individuals with disabilities. This version of self-determination is now the legal and ethical foundation for physician assisted suicide. Individuals can decide that their lives no longer have meaning. This is now considered a "right". What about those who are deemed "incompetent". How do they partake of this new "right"? Court appointed guardians charged with determining the "best interest" of the person with a cognitive disability are simply the logical extension of this doctrine. No longer do its proponents have to defend the refusal to authorize necessary medical treatment for a person with a disability; rather, guardians can be encouraged under this doctrine to see this as acting in the "best interest" of the person with a disability because they can now determine that death is a greater good than continued, prolonged disability. It is now considered an act of "kindness" to relieve someone with a significant disability of his or her very life. Recent and contemporary discussions both at the beginning of life and at the end of life no longer focus exclusively on the gray, ethically complex areas that surround decision making for individuals adjudicated incompetent. In fact, the discussion has moved from relieving the "burden" of disability for the person with a disability to relieving the burden to society that is associated with the public cost necessary to support someone with a disability. Furthermore, a lack of "competency" subjects the person with a disability to greater scrutiny in the allocation of public resources than someone without a cognitive disability.

That trend is a dangerous one of course. But the history of patient self-determination took another, more malignant, turn in recent years. The significance of autonomy alone as a foundation for this version of self-determination has grown in value such that those who are deemed not able to exercise basic decision-making are now seen as less valuable—less equal than those who can. This flows irrevocably from the definition of incompetence. The more "incompetent" the less self-determination becomes a possibility.

THE LOSS OR ABSENCE OF SELF-DETERMINATION OR AUTONOMY,

## DEPENDING ON THE SIGNIFICANCE OF A PERSON'S DISABILITY, THEN BEGINS TO LIMIT THE OBLIGATIONS OF SOCIETY TO PROVIDE NECESSARY LONG TERM SUPPORTS AND MEDICAL TREATMENT

How did the field of bioethics, medicine and law reach what appears to be a general consensus that individuals with significant disabilities are not equally entitled to society's resources? Contemporary outrage over the appointment in 1999 of the Australian ethicist, Peter Singer, to an endowed chair at Princeton University, is simply the latest case in point. Singer has argued that young children, babies surely, are not fully human and therefore not entitled to the same protections as "real" humans. Significantly disabled infants, Singer argues, are "non persons" and frequently do not reach the moral status of certain animals. Many advocates are alarmed by his appointment. Singer's views on the lack of humanity for newborns with disabilities can be examined as far back as 1979 when he published his text *Practical Ethics* and in 1984 when he wrote a "guest editorial" for *Pediatrics*, the *Journal of the American Academy of Pediatrics*. In that editorial he compared significantly disabled children unfavorably with pigs and dogs. (Singer, 1984). When Singer came to this country after experiencing massive protests in Europe against his views, *The New York Review of Books* accorded him a forum, what amounted to an apology for euthanasia. Singer titled this long essay "On Being Silenced in Germany" and compared himself to victims of Nazi oppression. (Singer, 1991) The question remains. From *Pediatrics* to *The New York Review of Books*. Just how far out of the mainstream is Peter Singer?

The attack on the value, the very humanity of persons with disabilities, the perceived lack of quality in their lives, their lack of humanness even, and, finally, their "prohibitive" cost to society, is recorded in the peer reviewed medical and ethical literature since the 1970s. The first important article in the peer reviewed medical literature began with physicians describing why they would not or did not treat certain infants based on "quality of life" considerations. Drs. Duff and Campbell were among the first and among the first to utilize the services of three of the most prestigious medical journals in the country: *Pediatrics*, the *Journal of the American Academy of Pediatrics*, *JAMA*, the *Journal of the American Medical Association* and *The New England Journal of Medicine*. (Duff & Campbell, 1973) There are several milestones in this literature that highlight this downward spiral.

University of Kansas Professor, Rutherford Turnbull, chronicled this literature through 1988 for the US Civil Rights Commission. (*Medical Discrimination Against Children with Disabilities*, 1989). The citations from the literature and the testimony of doctors and ethicists number in the

hundreds. It was during the period of the 1980s that the discussion moved from subjective "quality of life" arguments in favor of denying treatment to individuals with disabilities to social and cost related arguments.

In the aftermath of the celebrated Indiana "baby doe" case of 1983, where an infant with Down syndrome was "allowed" to starve to death, Dr. Walter Owens, the physician in attendance during the death of this child, testified:

In an ideal society, one might say we should consider only the welfare of the child, but this is not an ideal world and we do not have unlimited resources... Money which is spent... and we're talking of many times \$100,000 or \$500,000 or even one million dollars spent on these children... that is money that is not available for the education of normal children. (Walter Owens, M. D., 1986)

The experiment on children born with spina bifida at Oklahoma Children's Memorial Hospital was the most infamous. (Gross, Cox, Tatyrek, Pollay, and Barnes, 1983) Here, Dr. Gross and his colleagues reported that during the years 1977 to 1981, 33 infants born with spina bifida were selected for "non treatment". Of those for whom no objection was made, all died. The medical staff who conducted this "study" used a formula based on the potential financial contribution of family and society to the care of these children. Not unexpectedly, the children selected for death were poor. When Pulitzer Prize winning reporter, Carlton Sherwood, did a three part series for CNN in 1985 there was a brief public outcry. Carlton Sherwood had captured on camera a young black baby with a bubble on his back the size of a basketball. His mother, who was a single parent and on welfare, was counseled to give up her son. He was the latest child selected for non-treatment. The hospital and doctors resisted the entreaties of a nurse who begged for the operation needed and even offered to adopt the child. The National Right to Life Committee and the American Civil Liberties Union actually joined together in an action to sue the doctors and the hospital. It failed and this coalition predictably fell apart. The lead doctor in this macabre demonstration soon left for a position on the faculty of the Harvard Medical school and the nurse who exposed the behavior of the doctors to CNN was dismissed and prevented from working as a nurse again.

On the heels of this publication came the recommendation of prestigious group of doctors associated with the Brown University Medical School. (Walker, Feldman, Vohr & Oh, 1984) Several doctors at the Brown University Medical School published an article in Pediatrics the following



year that purportedly did a cost benefit analysis of low birth weight infants—247 infants who weighed between 500 grams and 999 grams at birth. Of all those followed for one to five years, most, 74%, were unimpaired or minimally impaired and 10% moderately impaired. What conclusion did they draw? Since they had determined that 16% would or did have "severe handicaps" none of the children in this birth weight category should be treated! Why? Their costs were too much for society to bear. Perfectly healthy children should be sacrificed so that society may relieve itself of the cost for a small minority.

Professor Turnbull in his research for the Civil Rights Commission came to the conclusion that lurking in the background of this kind of conduct was the spoken and unspoken bias against intellectual disability. The relevance of the cases and the literature surrounding disability issues at birth go right to the heart of the social prejudice against individuals with disabilities. Parents are almost always asked to act in the best interest of their children and are seen as their natural guardians. This is almost always positive. However, when the information provided to them is erroneous or biased, they may be led to decision making that more often than not conforms to this prejudice.

It was in April 1988 that Richard John Neuhaus, then Director of The Rockford Institute Center on Religion and Society, wrote about the return of eugenics:

Thousands of medical ethicists and bioethicists, as they are called, professionally guide the unthinkable on its passage through the debatable, on its way to becoming the justifiable until it is finally established as the unexceptional. Those who pause too long to ponder troubling questions along the way are likely to be told that "the profession has already passed that point." In truth, the profession is usually huffing and puffing to catch up with what is already being done without its moral blessing. (Neuhaus, 1988)

Buchanan and Brock's widely used text, *Deciding for Others, the Ethics of Surrogate Decision Making*, is now representative of generally accepted ethical and legal theory. (Buchanan and Brock, 1992). In this book the authors carve out two exceptional classes of individuals with disabilities: the "permanently unconscious" and the "severely and permanently demented". Neither class rates "personhood". In the first case society has "minimal interests" in providing care and treatment and in the second case "truncated interests" in doing so. The authors state:

Nevertheless, especially in the case of incompetent patients who are both unable to express their own wishes about care and whose debilitation limits the benefits they can receive from care (emphasis added) there is potential for the cost of care to loom large in decision making.

After serious examination of the issue of whether there is any general right to treatment (usually limited to medical treatment) for anyone, competent or not, the authors conclude that there is not. Patient self-determination is meant to create solely a right to refuse treatment and never a right to demand it. They continue then with their analysis:

Thus, when the incapacities that result in incompetence also reduce the benefits an incompetent patient can obtain from a given treatment, care may not be warranted that would be provided to competent patients as a matter of entitlement of individual right.

The authors go on to say that "...the severely demented are even worse off than animals such as dogs and horses...". Shades of Peter Singer.

In the 1990s when we were early on articulating the meaning and the implications of self-determination we came upon Sean. Sean was in a terrible auto accident and was wasting away first in a rehabilitation hospital and then a nursing home in a neighboring state. We administered the Medicaid waiver for acquired brain injury but simply did not have enough dollars to bring Sean home to his own community. Sean needed total care and was in a coma still after five years. The doctors called it a "persistent vegetative state". His mom and dad wanted him back because they recognized that the professionals had given up on their son.

We sat down with Sean's parents and simply said that we would put all of the money at our disposal under their control if we could figure out a way to bring Sean home. They immediately went out and secured a house, interviewed his high school friends for assistance and set up a network of individuals committed to Sean and whatever "recovery" might mean for him. Today a national brain injury group is making a movie of Sean's and his family and friends efforts. Sean and his mom and dad travel around the country giving presentations on self-determination. Sean is making eye contact and initial verbalizations.

Sean's dad one day articulated the danger he felt for his son. He simply said "How long will this society think my son important enough to continue this level of support?"

Once individuals get reduced to a status where personal autonomy or self-determination is not "possible", they may lose their moral claim on our resources. Contemporary ethicists like the authors above make this claim on the principle of distributive justice. Distributive justice underlies our progressive tax system, e.g., and simply calls for sharing resources in ways that approximate fairness. Distributive justice has been the cornerstone upon which we argued for resources for the most vulnerable. Contemporary ethical theory has now turned this principle on its head. Because we live in times of scarce resources, especially medical and long term care resources, those who can "benefit" the least (read those with significant disabilities) may end up having the lowest moral claim on these resources.

During the 1990s the discussion has intensified. Readers may remember the story of Sandra Jensen, the California woman with Down syndrome who needed a heart transplant. It was no mystery why she never made it onto a list of individuals for whom a heart transplant might become available. Only a large and public national outcry by her friends finally made it possible for her to receive the heart transplant.

During the last decade of this century Richard John Neuhaus's words have become prophetic. Chronic disability, and, especially "incompetence" associated with disability, has now created a duty to die. The Hastings Center Report regularly brings us new and disturbing articles advancing an agenda largely created by the new utilitarian ethics. Even the more thoughtful individuals associated with the Hastings Center, such as Daniel Callahan, its Director, have modified their views on important ethical issues surrounding individuals with disabilities in the last 15 years. In 1983 Callahan wrote forcefully against the idea of ever withdrawing food and water. He said " The feeding of the hungry, whether because they are poor or because they are physically unable to feed themselves, is the most fundamental of all human relationships. It is the perfect symbol of the fact that human life is inescapably social and communal." (Callahan, 1983) Less than four years after publication Callahan changed his mind. He then published his book "Setting Limits: Medical Goals in an aging Society". (Callahan, 1988) In this book he seeks to set out some principles that will help us establish limits on providing care based on a new social expectation that there is a "natural life span". In his review of the book, the American philosopher, Sidney Hook, takes Callahan to task for not going far enough. (Hook, 1988) Callahan's most recent contribution to a discussion of these issues has been to coin the term "the biologically tenuous" in order to assist us in discussing the rationing of medical and long term care for individuals who have reached the age of 85.

Rationing itself is still a topic that receives little attention. Irene Wielawski,

a journalist who writes on health care issues, calls it "...one of the most troubling and least talked-about-issues in health care: the rationing of medical care not by need but by the wealth of the patient." (Wielawski, 1999) The pressures to limit care are familiar in the context of the current managed care debate. The "ethical" community would seem an unlikely ally.

Arthur Caplan, who writes extensively on ethical questions, is one of the few to challenge the issue of the actual cost associated with caring for individuals at the end of life. The common wisdom is to associate the burgeoning costs of Medicare to the high cost associated with end of life care. He says "Sadly, the movement to encourage the use of living wills has as much to do with hopes for cost containment as it does with self-determination." (Caplan, 1993) While Caplan seems not to understand the communal role in self-determination, he did have the temerity to report on the data from the Health Care Financing Administration for Medicare expenditures from 1976 through 1988. Those in their last year of life accounted for 28.2 percent of Medicare expenditures in 1978 and in 1988 the number was 28.6 percent. Ironically, the older the patient got the smaller the cost to the Medicare program.

In 1997 John Hardwig wrote "Given our society's reluctance to permit physicians, let alone family members, to perform aid-in-dying, I believe I may well have a duty to end my life when I can see mental incapacity on the horizon." He went on to say:

Many people were outraged when Richard Lamm (former Governor of Colorado) claimed that old people had a duty to die. Modern medicine and an individualistic culture have seduced many to feel that they have a right to health care and a right to live, despite the burdens and costs to our families and society. But in fact there are circumstances when we have a duty to die. As modern medicine continues to save more of us from acute illnesses, it also delivers more of us over to chronic illnesses, allowing us to survive far longer than we can take care of ourselves. It may be that our technological sophistication coupled with a commitment to our loved ones generates a fairly widespread duty to die. (Hardwig, 1997)

Dr. Bob Edwards, the renowned embryologist who was part of the team that helped produce the first baby born using in vitro fertilization spoke at the annual meeting of the European Society of Human Reproduction and

Embryology in France of this year. According to the July 4, 1999, Times of London, he said that "Soon it will be a sin for parents to have a child that carries the heavy burden of genetic disease. We are entering a world where we have to consider the quality of our children."

A duty to die and a duty not to be born. We have indeed entered a brave new world.

In the field of law, medicine and ethics the issue has been essentially settled. Those with significant disabilities, especially those with significant cognitive disabilities, have lost a substantial claim on our resources within this elite community. Peter Singer and Jack Kevorkian are simply the popular and media savvy proponents of a theory that is becoming all too acceptable.

What may be necessary is to examine current notions of incompetence, significant disability and distributive justice. The notion of autonomy alone as a foundation for self-determination, if it ever held any promise, has failed the test of equality, equal citizenship and community. Amid conflicting data, the call for withdrawal of resources has reached a critical juncture.

To be sure, many parents seize upon guardianship as a way to protect their sons and daughters from the very dangers outlined above. In some states, unless you are a guardian you cannot obtain vital information and records needed to advocate for a person with a disability. However, the other side of the guardianship coin remains clear: thousands of individuals with disabilities across the country live with do not resuscitate orders; thousands more are confined to institutions. Most under the direction of a court appointed guardian or corporate guardian. This is illustrated in aspects of the current Connecticut institutional case, *Messier Vs State of CT*. In dispute is not only the issue of a corporate guardian prerogative to institutionalize an individual with a disability but the role of guardians in imposing do not resuscitate orders both at the institution and at nursing homes. A judicial finding of incompetence can result in real protection for some and death or banishment for others. We need to reassess our traditional commitment to guardianship and begin the arduous task of collecting more data on the dimensions of this problem.

### Equality as a Foundation for Self-Determination

The notion of informed consent was at the heart of the American Revolution. In our founding documents a theory of equality was enunciated that grounded equal rights as the centerpiece of a political philosophy, albeit one that has taken over two hundred years to become applicable to all Americans. The last groups surely are those who are routinely stripped of their citizenship in the name of providing help or, as it turns out, in the

name of denying necessary medical and long term supports. It is unclear how depriving individuals of constitutional protections can be truly helpful in the long term and in the face of this onslaught from the newly energized bioethics community, an attack no different in substance than the one mounted by the eugenics movement in the early decades of this century. Self-Determination as it is articulated under the rubric of equality, begins with freedom, includes responsibility, and forces us to grapple with the meaning of freedom for those who need assistance in exercising this right. Self-Determination grounded anywhere outside the Constitution and the Bill of Rights or an international declaration of rights, leads inexorably to a continued diminution of those rights. Self-Determination grounded even in pedagogy or psychology inevitably leads to "tests" for self-determination and, hence, we return to the employment of autonomy and skill based curricula as the last and final examination for meeting the test of citizenship. It will be up to all of us to withdraw our consent from any theory that increases the vulnerability of individuals with disabilities.

#### A NEW LEGAL AND ETHICAL FOUNDATION

One of the great advances in the field of developmental disability has been the evolution of person centered planning and increased recognition of the value of all communication--that stemming from typical and atypical behavior. With this knowledge we can begin to challenge current notions of competence and incompetence. Person centered planning requires outcomes based on the preferences of individuals with disabilities. Its implications for challenging incompetency are enormous. The next logical step is to assert the fact that no one is "incompetent". We need to recognize that many individuals will need assistance in decision making and that much resistance will arise from challenging accepted, indeed cherished notions in the field of law, medicine and ethics.

The grounding for this new approach will rest on both the notion of equal citizenship or equality and the provision of needed supports only from individuals who have a demonstrated commitment to the person with a disability.

Opposition will mount not only in the field of developmental disabilities but also in the field of aging where the numbers will be much greater in the next thirty years and the competition for limited resources will make today's discussion even more critical. We need to adopt a set of short and long term strategies. Only a new legal and philosophical foundation can lead us out of the morass of the new eugenics.

We have to reject the idea of incompetence as a wholesale inability to exercise rights and decision making. The Swedish statutes might provide some guidance here. We need to replace it with the idea of "assisted competence". This will include a range of supports that will

enable individuals with cognitive disabilities to receive assistance in decision making that will preserve their rights secured under law. This notion of assisted competence will be grounded in the ideal of equality and human rights. Political equality will become the context for discussing the idea of autonomy. The "self" in self-determination will be linked by definition to other, trusted individuals both family and friends who remain or become deeply committed to the individual with a disability.

We need to anchor the supports that individuals need firmly in our communities and focus on the importance of relationships, meaningful work, community connectedness, the need for intimate friendships and supports, and the contribution that individuals can and do make to our social and political life. Supports will be freely chosen with assistance when needed and self-determination will infuse all of these supports and the duration of these supports. Honoring the principles of self-determination will begin the process of ending the stigma of "incompetence". This means, among other things, a thorough re-examination of what currently passes for human services.

Services that isolate people with disabilities from our communities or that involve activities not highly valued by our culture will have to be replaced. Just as important is the moral imperative to achieve both equity in public spending as well as efficiency in per person allocations. This will mean that typical services organized around congregate models must be challenged as well. To the extent that typical services separate individuals from their communities they will be found wanting. To the extent that typical services fail the fundamental test of freedom and responsibility they will be superseded by highly individual supports that honor the wishes and legitimate dreams of folks with disabilities. Expenditures that exceed what a person needs to live a highly desirable life, because program models dictate them, will be seen as wasteful.

We need to begin drafting more respectful statutes that provide the assistance individuals may need without depriving them of basic civil and human rights. We will first end corporate and public types of guardianships because they do not meet the test of individual and personal commitment, and a shared, trusting and reciprocally generated relationship. Even under current statutes we need not wait for legal reform. Policy reform can lead the way. No one should ever be in the role of guardian unless that is acceptable to the person with a disability. The best interest standard will be replaced by representative decision making, i.e., the person in this legally assigned role, must do the intensive labor necessary to ascertain

what the person with a disability likes, prefers and dreams. In other words, even under current statutes, the receipt of public funds can be contingent on the presence of objective evidence that the person with a disability is experiencing supports and relationships that honor his or her own unique desires including who provides representative guardianship supports under current statutes.

With this new foundation we can begin to mount an offensive against the utilitarian agenda that is gradually being adopted in the field of law, medicine and ethics with no input from individuals with disabilities and their close family and allies. Reforming guardianship is, of course, only one of many strategies we need to adopt in order to counter this eugenic assault. Guardianship simply provides us with a starting point that will gradually lead us to reconsider so many other issues including the organization of current services and supports. There is a new voice that is just beginning to flex its political muscle on this and other important policy, legal and ethical issues in the field of disability. These are the groups of self advocates (individuals with disabilities) variously united under "People First". They carry the most legitimate moral authority to challenge eugenic interpretations of their lives. By creating an equal political partnership with parents and family members, they remain the only force capable of confronting this enormous prejudice. They will need many allies. Under this new rubric:

We can explore meaningful alternatives to guardianship. We can reject the notion of incompetence and replace it with a notion of assisted competence. We need to do this in statute as well and insure that it becomes more than a rhetorical device.

We can base all of our future work on the notion of political equality and equal rights as central to the idea of autonomy and self-determination. This may enable us to revisit the idea of distributive justice in ways that do not discriminate against those with disabilities.

We can insist that all supports provided to individuals with disabilities be based on assisted informed consent. This means that the system of long term care must change to place control of the dollars directly under the management of individuals with disabilities and their freely chosen allies. Freely chosen allies will include family members who advocate for these basic rights, friends, direct support staff who have reciprocal and trusting relationships as well as a variety of professionals who become committed to this philosophy.

We can then insist that the entire system of long term care become more equitable and that state expenditure patterns reflect adoption



of the principles of self-determination as they are embodied in the concepts of freedom and responsibility.

We need to reform the present system simply to address the mythology associated with the historic costs of long term care—costs associated more with models of congregation-- than individual support. Our obligation to be "cost effective", while simultaneously increasing the benefit to individuals with disabilities, will become a moral imperative. The wise and efficient use of public dollars must be apparent to the wider society and challenge the frequently erroneous or misleading data associated with the legal and ethical culture.

We will need to thoroughly evaluate our current "services" to insure that they are consistent with roles that are highly valued in this society. Programs that diminish the stature of individuals with disabilities will need to be abandoned. Those with conflicts of interest concerning the operation of the current system will need to be engaged. Opportunities for individuals to contribute to their communities, earn real income and forge, distinctive, highly meaningful lives for themselves, will become paramount. Otherwise, the stigma of incompetence will remain as a social weapon to justify the unacceptable.

This new foundation must be based upon equality, shared vulnerability and a deeper sense of community that we all create in our own distinctive ways. We need, simply, to create a new legal and ethical foundation for protecting vulnerable adults and children as well as those who care about them without diminishing their legal or social stature. We will in the process be constructing a more humane system for all of us as we begin to recognize our own vulnerability. Reform of guardianship and promotion of self-determination will proceed hand in hand. They are mutually reinforcing.

Yale University legal scholar, Robert A. Burt, long a voice of caution concerning contemporary legal and ethical theory, in an essay entitled "The Suppressed Legacy of Nuremberg", speaks to the vulnerability that all of us share as he challenges the isolationist view of autonomy and self-determination: "...the confident assertion of the self-determination right leaves unacknowledged and unanswered a crucial background question: who can be trusted to care for me when I am too vulnerable and fearful to care for myself?" (Burt, 1996)

What Burt is doing is simply drawing all of us into the same equation, a shared sense of mutual vulnerability. In our context it means that we are more alike and vulnerable than we might think. We share this vulnerability with individuals with disabilities and plainly need to create a society, based

on an ethic if you will, that will make us all comfortable with the ability to put our trust in others (including those who represent medicine and law) but especially in those with whom we have created enduring relationships, ordinary community members and, finally, a new force of professionals. We are a long way from that vision today. Overcoming such a long history of prejudice requires a lifetime of work, the engagement of political interests, and a new vision of a just society.

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