



Alliance for Freedom News

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To: Our Liberal Friends

From: Tom Nerney

Re: The Death of Terri Schiavo

We need to have a serious conversation. We thought we had forged a great history with liberal support in order to secure basic rights for individuals with disabilities. Some of us remember the crafting of the first federal disability rights law. Into section 504 of the 1970's Rehabilitation Act we copied word for word whole expressions taken from the Civil Rights Act of 1964. Since then many in the disability community thought that your basic support for the ADA and other important federal and state legislation was a result of your commitment to the disability rights movement. After all we had so many times participated in various parts of the civil rights movement and finally saw the exclusion of people with disabilities from basic protections as another example of the work we had to do. And now we have to wonder. We just lost you so thoroughly on the central life and death issue that arose over the legal and court battles to save Terri Schiavo. Where did you go? Perhaps you don't understand that Terri Schiavo was simply the latest in a long list of individuals with various disabilities put to death.

People who experience disability and their true allies understood from the beginning the high stakes of the Schiavo case. We were dismayed with how it played out in the media as a right to life versus a right to die drama with liberal support for ending her life so prominent. Ed Roberts, one of the founders of the independent living movement, used to begin all of his talks across the country with a reflection on what his parents were told about him. He was labeled by his doctors as a vegetable. So he would begin his talk by choosing which kind of vegetable he was to be that day. He used gentle humor to bring attention to the misuse of language. Ed Roberts though got his own revenge again in a very gentle way. Turned down by the California Department of Rehabilitative Services for being "too disabled" he later rose to become its director.

What we found to be in a persistent vegetative state was the level of discourse about the issues raised by all sides. The virtual silencing of disability leaders by the media was part of our dismay. There were a few on both sides of the political spectrum who acted nobly. Just a few though. More on two of them later. Many of us were deeply disturbed. Disturbed for both procedural and substantive rights that were ignored and indeed trounced. All of us are concerned about the importance of end of life issues and good people can sometimes hold differing opinions on the best course of action to take. We recognize the complexities and raw emotions that can surface during times of such stress. There is however a problem. Terri Schiavo wasn't dying.

I thought it important to begin this conversation by spelling out the particulars of this

hold in a newly
designed system

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case that need to be addressed by those of you who are still willing to reflect on what you have, so completely and willingly it seems, endorsed for people with disabilities. So, this will be a difficult conversation. Let me start by pointing out that you completely ignored the real experts on these issues. The leaders of Not Dead Yet, Diane Coleman and Stephen Drake summed up the frustrations of disability rights activists very well. They wrote “People on the right are killing us slowly with cuts to the budget and Medicaid.” But they reserved special anger for liberals by adding “People on the left kill us quickly and call it compassion. Either way we end up dead—AND WE OBJECT.”

We saw how you so completely endorsed the right of Michael Schiavo to end her life. A husband in name only he was consumed by important economic and personal conflicts of interest that should have nudged any competent judiciary to remove his guardianship. Would you have been so supportive if he had taken the position of her parents? People with disabilities know this issue well. Today, thousands of individuals with significant disabilities, many in nursing homes and institutions, are living with “do not resuscitate” orders even though they are not dying. We have given guardians life and death control over persons with disabilities and too many of them question the very value of the lives they are sworn to support. This should not have been a difficult issue for you. But you determined that Terri Schiavo’s life had no value. We recognize a sentence of death when we hear it. You may believe that the “facts” in this case were clear. We have ample reason and history to be suspicious. We wondered every day during this media frenzy when you too would share some doubts with us.

Who did you consult on these important life and death issues? Certainly not people with disabilities themselves. Would you ever address an issue of importance to members of disenfranchised groups, women and people of color come to mind, without finding out exactly how they thought and what they said was needed? Many of you moved immediately to the doctors that promote these practices and their frequent allies in death-making referred to as ethicists. I use the term loosely here. The disability community has rightfully challenged the rise of a group of so called “ethicists” founded on a utilitarian ethical theory that works invidiously to compromise the very lives of individuals who experience disability. Perhaps you know of Peter Singer who not long ago was given an endowed chair at Princeton University? Starting in the early 1980’s he began calling for the killing of babies born with disabilities. In the pages of Pediatrics, the Journal of the American Academy of Pediatrics, he wrote in 1983 about babies born with significant disabilities and compared them unfavorably with pigs and dogs. This is an issue that dates back to Plato and Aristotle who never tried to hide their contempt of people with disabilities.

1983 was the same year that a baby born with Down syndrome was allowed to starve to death in Indiana. Terri Schiavo was not first but just the most recent. We didn’t see any letters to the editor of Pediatrics from any of you. You were mostly silent on the starvation of that baby. Perhaps we should have been worried all along. But we are an optimistic group. We thought too that when the killing of babies with Spina Bifida at Oklahoma Children’s Memorial Hospital was exposed during this same time that we would finally see justice done. That was not to be. When those who allowed mostly poor and mostly minority babies, fully capable of benefiting from surgery, to die lingering deaths we thought we would finally see that the “new ethics” would be stopped in its tracks. We thought during the 1990’s that the terrible behavior of Jack Kevorkian would lead to reconsideration. But your criticisms of Kevorkian were targeted at his methods and his crudeness not his agenda. So Kevorkian went to jail on a technicality while so few raised the question of the deep depression those mostly women experienced who sought his “assistance.”

Peter Singer and others like him now dominate the field of bioethics as it is fashionably called. When he returned from a trip to Europe where he was shouted down by a large group of people who use wheelchairs, he published an apology and attacked his critics with disabilities in the pages of *The New York Review* where he has been frequently published.

Where are you on the important issue of the reemergence of eugenics? From doctor assisted suicide to euthanasia of infants with disabilities the very existence of disability has become in itself a rationale for death. How far will this go? Where is the liberal equivalent of Richard John Neuhaus who in 1988 wrote in the pages of *Commentary*:

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.

Perhaps you can also answer our question on just when food and water became a medical intervention. For all of Western civilization food and water has been viewed as normal sustenance and a universal right. Medically supervised starvation and that is exactly what happened to Terri Shiavo, is a new weapon of choice now targeted at individuals who require better representation and standards than our current guardianship laws allow and bioethical theories that don't devalue and call into question the very lives of these individuals. Plain old discrimination is dressed up in fancy new language that includes the word compassion. This is indeed a brave new world but one that people with disabilities rightly fear in what appears to be a never ending downward spiral.

Perhaps our friends in the liberal community have not adequately acquainted themselves with a history of discrimination that rivals the worst of what happened to persons of color. Perhaps you have been seduced by the new bioethicists who argue that the recent rise of medical technology has given new impetus to their ethical theories and writings and pronouncements. The truth is far different. The rise of the eugenics movement in the first half of the 20th Century covered all the issues. Contemporary bioethicists do not have a hold on "compassion" as a marketing tool. It was first advanced by a vicious eugenicist in 1941 and 1942 as a way to finally address the killing of people with disabilities with impunity.

After the turn of the 20th Century all of the Jim Crow segregation statutes but one were passed. All of the gains made through Reconstruction were wiped out and an entire population of people of color became totally disenfranchised. At the same time another series of segregation statutes swept the country. They only differed from the Jim Crow statutes in the viciousness of their wording. In the state of Washington in 1909 children with disabilities were called unfit for companionship with other children. In 1920 in Mississippi people with intellectual disabilities were deemed "unfit for citizenship." In 1919 Alabama declared by law that people with disabilities were "a menace to the happiness of the community." In 1916 Vermont called people with disabilities a "blight on mankind." You get the picture. No state was spared. In 1912 the Massachusetts Medical Society called people with disabilities a "parasitic, predatory class."

During these years over 30 cities passed ordinances barring individuals with disabilities of even being seen on the streets. The Chicago ordinance read that no person "diseased, maimed, mutilated or in any way deformed, so as to be unsightly; could be seen in any public place. In 1932 the District of Columbia urged Congress to authorize putting people with disabilities away. The Congress

agreed.

In 2000 the Smithsonian created a memorial to Bertha Flatten as part of its exhibit on civil rights in the Twentieth Century. Bertha Flatten died in 1905. She died at the Faribault Institution in Minnesota and she was buried in an unmarked grave stamped with the number seven. That number seven and that brick were moved to the Smithsonian so that we can begin to understand what we did to individuals with disabilities in the first part of the Twentieth Century. A majority of states still keep people with disabilities in state institutions. They remain today America's internal exiles.

But the story doesn't end there of course. In 1915 a Chicago surgeon broke the silence around his and other doctor's refusal to treat babies with disabilities. The story was so big that in many cases it pushed World War 1 off the front page. His name was Dr. Harry Haiselden and he lectured widely around the country to stop the medical treatment of children with disabilities. He wrote the script and starred in a movie he developed for the public called *The Black Stork*. Dr. Martin Pernick chronicles the enormous influence of this vicious movie in his book called *The Black Stork*. It was shown in commercial theatres from 1916 through the 1920's and then reissued under a new title, *Are You Fit to Marry*, and continued to be shown in small theatres and traveling shows up until the 1940's. Leading Americans endorsed his crusade. His legacy lives on.

The assault against people with disabilities continued unabated until the Second World War. 17 states passed sterilization statutes aimed at criminals and persons with disabilities. But in 1942 a formal proposal to kill those born with disabilities was advanced by one of the most prominent neurologist of the day, Foster Kennedy. Writing in the *Journal of American Psychiatry* Kennedy proposed a protocol for killing that resembled what the Nazis had already advanced. But the words Kennedy used haunt us forever. He said that allowing people with disabilities to live was "sheer sentimentality and cruel, too." And then he went on to say that we may kill without fear of error and called his proposal for killing "kindly." A young Jewish doctor at that time, Leo Kanner, wrote that he did not think it was a good idea to emulate the Nazis. The editors of the *Journal* included an article that endorsed Kennedy and suggested strongly that parents who continued to love these children were fit candidates for psychiatry's care.

Spare us from this continuing reference to your compassion and kindness. It doesn't pass the smell test of history. Putting people with disabilities to death has remained on the American agenda for over 100 years. The contemporary academic medical and bioethical citations supporting the killing of people who experience disability would fill a volume by itself. The attack on the value of people with disabilities is unrelenting. During the media circus over Terri Schiavo some took hope from two elected officials -one from the left and one from the right. Senator Tom Harkin of Iowa called a press conference and raised the issue of how causing her death might be wrong. He rightly raised the issue of other people with disabilities who might be similarly targeted. Senator Harkin had the human decency to be troubled by the deliberate starvation of another person. Another elected official played an important role in the Schiavo case. He is the Governor of Florida, Jeb Bush. His defense of Terri Schiavo was based on his sincere religious and conservative convictions. What is seldom reported, however, is that as Governor he has almost doubled the amount of money in the Florida Medicaid long term care system for people with significant disabilities. That kind of compassionate conservatism we can live with. Literally.

This is a long letter. So much more could be said. The questions are still there and we must at some point decide if a very long and productive conversation is ever going to take place between us. It may be too late. I hope not. Perhaps you can initially agree

that that the exile of persons with disabilities was wrong and our past practices an abomination. At least twelve states have ended this practice. At least two states have formally apologized for the practice of sterilizing individuals with disabilities. Virginia was the first. Hope springs eternally with us.

I am reminded of a more personal story. Years ago I attended a meeting followed by a dance of a group of individuals who called themselves "People First." They are a group of people who experience intellectual disabilities but who have decided to speak out for themselves. They may not be well known but are a growing force in the disability community. I left the dance floor in awe of a young man who had Down syndrome. It wasn't just that he was a better dancer. He was more handsome. I learned later that he had a famous father. One I had known back during the height of the civil rights movement.

His dad was Arthur Miller. An icon of the American left and an inspiration to so many of you. Arthur Miller never publicly acknowledged his son. In fact his son was institutionalized like so many others over the past century. He did agree to allow his son to leave the institution for the community some years ago. You have to recognize the terrible effect of America's obsession with denying the value of individuals born with a disability. Yet, there is hope again. While Arthur Miller never did publicly admit that he had a son with Down syndrome, he responded not long ago to a local advocacy group who asked him if he would help with their mission. They were the group largely responsible for filing suit against the institution, for advocating for all individuals with disabilities, for holding out the promise especially for those with intellectual disabilities. His answer was yes.

We don't expect a complete change of heart. Simply a willingness to talk about these hard issues. For starters it would be thoughtful of you if you took a cue from Senator Harkin and allowed that you too may be troubled. What you don't seem to understand from the issue of Terri Schiavo was not our position that she should be kept alive at all costs and in spite of all evidence. She was not dying and not suffering. Terri Schiavo scares us because she represented for all of us our own vulnerability. She needed to be cared for so completely. We will never know what her own wishes were and she will forever represent what we are most scared about. That might be why we so frequently say that folks are better off dead than to be in any condition that represents a loss of complete control. Especially our intellects.

Then we could begin talking seriously. Then we can get down to discussing how we sent so many thousands of people with disabilities into exile where so many remain trapped today in our public institutions and our nursing homes. Like Arthur Miller maybe you will also say yes.

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