

APPENDIX G:

ADRIENNE ASCH'S COMMENTS AT THE OCTOBER 2007 ASPE ROUNDTABLE

HOW WOULD END-OF-LIFE CARE, ADVANCE CARE PLANNING, AND ADVANCE DIRECTIVES BE DIFFERENT IF PERSONS WITH DISABILITIES WERE INVOLVED FROM THE START?

Thank you. Thank you for allowing me to present. I think this is an important opportunity. I guess I would say, I think, three things:

First, although there may be some particular concerns that people within what is sometimes called 'the disability community' have about how they themselves will be treated, the perspective that I'm interested in advancing here is not so much about members of the disability community, that is people who've had long-standing intellectual, psychiatric, physical, sensory conditions, but what lessons that community has to teach the entire end of life movement. Remember, we know but I think we forget sometimes...even in having a separate conversation about disability and end of life. At the point where you're talking about end of life care, whatever that means, we are talking about people with a range of chronic or degenerative or possibly terminal conditions. They are all, by any definition, people with disabilities, impairments. They would come under the Americans with Disabilities Act. They now have limitations of substantial life activities of all sorts. Even the courts that have narrowed the definition of disability under the Americans with Disabilities Act are going to include all the people we are talking about today and tomorrow. Alan, Nancy, Charlie if you think I'm wrong, fine, but you're lawyers and I'm not, but I think I know how to read the act.

So, I'm interested in raising what I think had the literature -- and there has been literature by people with disabilities from within bioethics and outside for over 20 years -- so I must say it's still rather frustrating to see it not cited in many places where it should be cited. Had that literature been read and used I think things could have been and would be very different on several scores.

First of all, the people with disabilities and the so-called disability community concerns would not be talked about in the same paragraph or frequently the same sentence as evangelical right-to-life and life protection groups. They share almost nothing in common with those groups, from the standpoint that the arguments made about why life might wish to be preserved by people and why we might want to think about whether patients want to preserve their lives, as opposed to end them, have little to do with anything called sanctity of life. [Instead], they are about quality of life and they are about how to make lives with illness, impairment, degenerative conditions, terminal illnesses, chronic disabilities as satisfying and rewarding as possible.

They start from the premise not of ignoring patient self-determination and not even of ignoring the concerns of family, but from the premise that the societal understanding of disability and illness and dying needs to be rethought. It's not merely one of isolation,

stigma, prejudice, but it's often, as Robert Burt pointed out as early as 1979 in his discussion of the Dax case. Intertwined with wishes to help vulnerable, sometimes distasteful, physically ugly, incontinent, embarrassing people, are wishes to hurt them and obliterate them...and we don't like to think about that, but we have to ask whether the health professional, the family, the society is in fact very uncomfortable with degeneration and decline.

And the patient's wish to end treatment, if that [is] in fact a patient's wish may come as much from her or his fears that other people feel that about him or her and ways that she or he has to some extent internalized those fears as from deep-seated, long-lasting views for those patients themselves about what kind of life they want.

Let me try to say that a little less circuitously. Yes, let's look at patients' genuine wishes, but work at assessing what those wishes are, not by such things as "do you want a ventilator?" "do you want a feeding tube?" but "what will give your life meaning?" What do we need to help you give your life meaning? What techniques can we who are not cognitively or sensorally...or auditorily or visually or mobility impaired do to help you with our abundant health care, physical, [and] social service resources to help you make your life as meaningful as possible and help you sustain the activities that matter to you for as long as you would like them sustained. If we stop thinking about diapers and catheters as examples of indignity and simply recognize that they are methods that people use to keep themselves clean...the dignity is in the eye of the beholder. If we stop talking about wheelchairs as confining but recognize them as liberating, which they are, we can recognize that people can live with a range of methods of getting their needs and making their activities met. Instead of talking about people with special needs, recognizing that people have the same human needs for interaction, responsivity, giving and receiving affection, making contributions of whatever sort and simply recognizing that tools -- ventilators, feeding tubes, etc. -- are simply methods of accomplishing the tasks that let people keep going to do the things that they want -- to meet the ordinary human needs that everybody has.

So one difference -- if people with disabilities and what they had been saying about everyone had been taken seriously -- would be that advance directives as provided would be very different. The questions people would be asked would not be about treatments and modalities and treatment choices, but about what do people want in their lives as they are dying. What are the things that people want in order to help them keep going? What capacities do they want to maintain? What activities do they want? Again, some of the person-centered planning ideas that Gary Stein discusses in his paper for people with intellectual disabilities, person-centered planning is what we want for everyone.

So, the biggest point is: take what people with disabilities are saying about themselves and recognize that it applies to everyone facing an end of life situation. Think about what people with lifelong or long-standing disabilities can teach non-disabled people. Put their expertise on ethics committees in hospitals. Ensure that people with disabilities and disability rights centers and experts in rehabilitation are

training geriatric, oncology, [and] neo-natal providers of care who rarely get quality information about life with disability outside of an acute medical setting. That applies sometimes to rehabilitation professionals themselves who also don't learn much about life outside of an acute medical setting.

So use the expertise of people with disabilities on ethics committees. Use the expertise of people with disabilities in helping rewrite the kind of advance directives given to everyone. Rethink how we view the tools that people with disabilities can use to lead their lives for however long they want to lead them and think about capacities, activities and meaning in life and not diminishments, deficits, disasters, tragedy, burden.

If we think about disability and dying only as burdening to others -- when we look at the Oregon physician assisted suicide data we find that the reasons people desire physician assisted suicide have much less to do with physical pain, and much more to do with fears of loss of control over their lives, fears of abandonment -- then what that means is that we have to help people who are not requesting physician assisted suicide, but newly disabled, now terminally ill people fearing that they will drain their loved ones energies and commitments to them and change. Therefore, give them some help and give their loved ones help in figuring out ways not to be or not to feel burdened. That's not a simple task.

I'm talking about changing health systems as well as family attitudes. I'm recognizing that what I'm calling for requires resources and social services that we don't entirely have and some responses to what I'm saying will be you're dreaming of an idealistic world that we don't have and that the political climate isn't going to get us. That may be, but if you're asking what I think would change in the end of life field if lessons from people with disabilities were taken seriously, these are some of the lessons and that would change the way resources are allocated and what resources are allocated to help people -- patients and their families -- think about end of life and how to make life meaningful and valuable for everyone as long...as they want to live it. It would not be an assumption that people never want to withdraw treatment, but it would be an assumption that people might want treatment as often as they want it withdrawn.

And the last thing I would say for people with intellectual disability, cognitive impairments, again the matter of decisional capacity that's been framed in Gary's paper and the work by Ruth Freedman and Anne Botsford and other people that are here around the table...These point the way for using the capacities that people with disabilities have and as it applies to the newly disabled person with Alzheimer's, Parkinson's, or after a stroke, remember that a family's sense of tragedy and deficit and loss can overwhelm a family's sense that the patient still has contributions to make of some sort to other people's lives, [and] can overwhelm the sense that a patient will find life meaningful in some way even if [it is] no longer the way they felt before the onset of dementia or the stroke. And be wary of too quick presumptions that famil[ies] know the interests of now very decisionally-impaired individuals. Be aware of the misdiagnosis that Joe Fins can talk much more about in minimally conscious people. Recognize that it is easy out of fear, loss, grief, anger, for people to give up on now very, very disabled

individuals and recognize that in the absence of very clear evidence that a now very impaired person really does not want treatment and does not feel that life can be meaningful.

The presumption should be in terms of treatment unless the treatment is going to be burdensome and meaningless and will only prolong the dying process. Whether the standard should be clear and convincing evidence as it is in New York and as I know many people object to, I don't know. But I think it really does need to be a very high standard that [we meet] before we give up on people's desire to live, if they have it. So change the kinds of advance directives that people get in order to fill them out. Use the expertise of people with disabilities on ethics committees. Recognize that the newly disabled dying, terminally ill person has joined a minority that they never necessarily wanted to join, but there they are, and give them the chance to learn from people more experienced in life in that particular minority category. And don't give up on people with diminished capacity quickly unless we have very clear documentation that people themselves do not want to live in that state. Recognize that family may not have good notions of what the patient might want -- they might, but they might not. The notion of best respect rather than best interest or rather than substituted judgment might be a good notion to bring into this end of life discussion not merely for people with long-standing cognitive impairments, but for everyone. Thank you.

ADVANCE DIRECTIVES AND ADVANCE CARE PLANNING: REPORT TO CONGRESS

Files Available for This Report

Main Report

HTML: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt.htm>

PDF: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt.pdf>

APPENDIX A. Methods

HTML: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt.htm#appendA>

PDF: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt-A.pdf>

APPENDIX B. Literature Review on Advance Directives

HTML: <http://aspe.hhs.gov/daltcp/reports/2007/advdirlr.htm>

PDF: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt-B.pdf>

APPENDIX C. Advance Directives and Advance Care Planning: Legal and Policy Issues

HTML: <http://aspe.hhs.gov/daltcp/reports/2007/adacplpi.htm>

PDF: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt-C.pdf>

APPENDIX D. Advance Directives and Advance Care Planning for People with Intellectual and Physical Disabilities

HTML: <http://aspe.hhs.gov/daltcp/reports/2007/adacp.htm>

PDF: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt-D.pdf>

APPENDIX E. Commissioned Report: Advance Care Planning and Public Engagement

HTML: <http://aspe.hhs.gov/daltcp/reports/2007/acppe.htm>

PDF: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt-E.pdf>

APPENDIX F. Roundtable Materials

HTML: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt.htm#appendF>

PDF: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt-F.pdf>

APPENDIX G. Adrienne Asch's Comments at the October 2007 ASPE Roundtable

HTML: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt.htm#appendG>

PDF: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt-G.pdf>

APPENDIX H. Summary of the Roundtable Discussions on Advance Directives and Advance Care Planning

HTML: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt.htm#appendH>

PDF: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt-H.pdf>