Response to Draft General Comment 6

on the Right of Persons with Disabilities to

Equality and Non-Discrimination (Article 5)

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***Summary*: Discriminatory withdrawal of protection against suicide is increasingly being proposed for persons with severe disabilities. (See e.g. Paragraph 10 of the Draft General Comment on Article 6 of the International Covenant on Civil and Political Rights, proposing diminished protection for such persons.) This discriminatory withdrawal of protection endangers not only the lives but also the human dignity and support relationships of persons with disabilities. Therefore, it should be explicitly forbidden by this General Comment 6 on the Right of Persons with Disabilities to Equality and Non-Discrimination (article 5).**

Putting aside the grave danger that “freedom of choice to die” might simply provide a cover under which seriously disabled people might be put to death involuntarily, there is also a threat of greater isolation, of a diminished quality of life, for those who choose freely to continue to live. Their worst suffering may not be physical immobility or pain, which can be alleviated with competent medical care, but feelings of isolation and hopelessness. The realization that others—or society as a whole—may see their death as an acceptable or even desirable solution to their problems can only magnify this kind of suffering.

When choosing to die is *not* seen to be an option, we are able to imagine those who battle to the end against serious illness or disabling conditions to be heroes struggling against an implacable fate. Their lives and their deaths are full of meaning. If an ailing grandmother fights to live on, despite her pain and her disabilities, she may so inspire her family that they feel privileged to share in some of her burdens as they care for her. At the least, she can be the object of sympathy in her misfortunes, and all can feel solidarity with her and with each other as they fight back at her side. Friends and the wider society around her can have similar experiences, though probably to a lesser degree. Insurance or governmental aid may also seem to be well-deserved. When death finally comes, her last experiences and the lasting memories of her friends and family can well be of a community bound together through her.

By contrast, a special right of a person with severe disabilities to assisted suicide or voluntary euthanasia means that her life has been deemed especially expendable, that her continued existence is legally less important than that of her fellow human beings.

Moreover, once she has been given a way out, her suffering may well seem no longer to call for as much family compassion or social support. Dr. Ezekiel Emanuel, a cancer specialist later appointed by former U.S. President Barack Obama to be healthcare advisor to the American federal Office of Management and Budget, has explained:

“Broad legalization of physician-assisted suicide and euthanasia would have the paradoxical effect of making patients seem to be responsible for their own suffering. Rather than being seen primarily as the victims of pain and suffering caused by disease, patients would be seen as having the power to end their suffering by agreeing to an injection or taking some pills; refusing would mean that living through the pain was the patient’s decision, the patient’s responsibility. Placing the blame on the patient would reduce the motivation of caregivers to provide the extra care that might be required, and would ease guilt if the care fell short. Such an easy, thoughtless shift of responsibility is probably what makes most hospice workers so deeply opposed to physician-assisted suicide and euthanasia.” *Whose Right to Die?* Atlantic Monthly73, 79 (March, 1997).

“Her choice, her problem,” many will think, just as they may think regarding the mother who knowingly gives birth to a child with a Down syndrome disability. If a grandmother chooses to go on living, her suffering becomes her own fault, especially once assisted suicide becomes commonplace and thus normalized. Not impersonal fate but her own personal choice, the choice to live, will then seem to weigh them all down. Assuming she is not abandoned, she may be helped only grudgingly, and be blamed for any costs her continued existence imposes on other family members or on society.

In choosing to continue living in great dependency, a grandmother may be felt to be deeply selfish, preferring to benefit herself at a heavy cost to her family. As the benefit she receives grows smaller in their eyes—as she nears death or becomes more laden with pains or disabilities—her seeming selfishness increases; she prefers an ever-smaller benefit to herself in exchange for that great cost to the family. If she soldiers on to the point where her caregivers judge her life to be a cost to her as well as to them, she becomes for them irrational as well as selfish. Her right to choose thus brings with it a cruel paradox, if she insists on living: As her misery and consequent need for help increases, her family’s sympathy decreases. Politeness may prevent family candor, but the person with disabilities may still know what they are thinking: “What an absolute waste of the grandchildren’s money for schooling!”

Internalizing this criticism, a loving grandmother will constantly wonder whether she is being too selfish even in continuing to eat, when the money could have been saved for her grandchildren’s education or for some other good purpose. Agonized by guilt, she may sense herself drowning in a sea of resentment, and she may well be remembered as an irrationally selfish human being, unless she ultimately gives in and agrees to commit suicide.

Because legalization of the choice to commit suicide because of serious disabilities has such unavoidable negative effects on persons with such disabilities, it should be opposed *in toto* by the Committee’s Comment.

However, if complete opposition to the option of suicide because of serious disabilities is deemed unwise, I suggest the paragraph found below as a modest minimum level of protection.

Comparing the explanation above with the five forms of discrimination introduced in the Draft General Comment, I would at a minimum include ‘discriminatory withdrawal of protection against suicide’ within the meaning of harassment. I therefore suggest the following amendment for paragraph 20.d.

“Harassment”, which shall be deemed a form of discrimination when any unwanted conduct takes place with the purpose or effect of: violating the dignity of a person; and creating an intimidating, hostile, degrading, humiliating or offensive environment. For instance, making fun of a disability or abusive and threatening comments about someone’s disability are examples of harassment. “Bullying” and its online forms, “cyber bullying” and “cyber hate”, also constitute particularly violent and harmful forms of harassment. Due to the increasing adoption of national legislation regarding assisted suicide and voluntary euthanasia, harassment is developing in connection with such options. When allowed by national legislation, the choice to die has to reflect the will and preferences of the person only (see Article 12 CRPD). The individual must not be pushed by any kind of social pressure, which should be considered discrimination. The Member States cannot diminish their level of assistance considering the death of the person a better solution: this constitutes indirect discrimination and causes harassment. Persons with disabilities who choose to live, must have the opportunity to live with dignity.

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