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United Nations High Commissioner for Human Rights

attn.: Special Rapporteur on the rights of persons with disabilities

Re: Bioethics and Disabilities

Dear Ms. Catalina Devandas-Aguilar:

Thank you for leading this inquiry. Your work on bioethics and disabilities should start with the basics: international laws relating to the legal rights of persons with disabilities and the rights of children. My colleagues at the International Federation for Spinal Bifida and Hydrocephalus (IF) address these issues in greater detail in their comments, but I want to emphasize in mine the frequently ignored applicability of these international standards to decisions and policies that are categorized as bioethics matters - rather than as human rights issues in the bioethical context

My background. My brother has endured 4 decades of schizophrenia and my family has had to navigate the difficult issues of care, expenses, prejudice, individual rights and bureaucracy as well as the heartbreak of his broken mind as we worked to provide him with both safety and respect. My spouse is a stroke survivor. I am a public interest lawyer with 40 years of work for people with disabilities. I am a legal consultant with IF and authored *Disability Stereotypes, International Human Rights and the Groningen Protocol’s Recommendations for Ending Infants’ Lives* addressing prejudice-based harm to children with severe disabilities and violations of the United Nations Convention on the Rights of Persons with Disabilities and the Convention on Rights of the Child. See: <https://papers.ssrn.com/sol3/papers.cfm?abstract_id=1576285>.

Rather than repeating points made in that paper, let me state how a good portion of your analysis should proceed.

1. The principles and specifics of these U.N. conventions should be fundamental in examining bioethical issues in diagnosis, counseling, informed consent and treatment (or non-treatment) decisions. As you know, the Conventions do not provide easy solutions to the hard issues in bioethics in the context of disability. But they do give guideposts and suggest processes for policies and balanced decision-making in this difficult field. Philosophical, religious, economic, cultural and personal factors will all effect how bioethical decisions are made, but the U.N., member nations and interested parties can start with the Conventions and have a better chance of having legal and ethical outcomes.
2. Each time a bioethical decision or policy is considered, the U.N. and member states and interested parties ought to consider whether the premises underlying the decision or policy is based on the disability status or youth of the person involved. As related in my paper, above, frequently policies and practices that can harm adults and children with disabilities are explicitly or implicitly justified either because of their disability or age. That violates those Conventions. This comment is not to suggest that babies or people with disabilities should always be treated exactly as a non-disabled adult might be, but rather to direct decision-makers to consider whether illegal stereotypes result in prejudgment of difficult bioethical decisions. And thus violate the U.N. Conventions.

Thank you for this opportunity to be heard.

James E. Wilkinson