



Ethical and Legal Issues in Neurology: Chapter 21.

Ethics in neurodevelopmental disability

(Handbook of Clinical Neurology)

Eric Racine, Emily Bell, Michael Shevell

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Neurodevelopmental disabilities, like autism spectrum disorders and cerebral palsy are a common health problem in children. Given the impact of these conditions on children, families, and healthcare and social systems, the care of developmentally challenged children raises questions related to values and ethical principles. We review the common features of neurodevelopmental disorders that help understand the associated ethical questions. We focus on three major areas where ethical questions arise for clinicians and those involved in making decisions for or caring for these children: (1) the principles of decision-making and autonomy as they relate to developmental disability; (2) the issues related to quality of life that have long intersected with developmental disability; and (3) the use of unproven therapies and diagnostics that are particularly controversial given the extent that neurodevelopmental disabilities impact children and their families, yet active treatments options are limited.

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