

Levine, R. (2011). Incorporating the disability community's interests into healthcare reform in the era of genomics.

Abstract

The United States is in the early stages of transformations in the healthcare system. At the same time, recent advances in genetic research have significant implications for defining appropriate care. Definitions of concepts such as health, disability and disease in healthcare laws and practice guidelines may shape social and medical perceptions of those who experience such conditions, insurance coverage, access to social and medical services, and the overall quality of life. As genetic research is translated into medical practice, it is important to recognize the interests of disabled patients. Current discussions regarding incorporating genetic research into healthcare have failed to recognize the notions of "health" and "disability" as fluid concepts with multiple dimensions. Understanding political, social, and legal implications of defining these concepts is necessary to prevent creating a social structure that makes individuals with disabilities feel compelled to make medical decisions that they otherwise might view as against their interests.