Expanding Opportunities for People with Disabilities: Promoting a More Cautious Approach

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The articles in this special issue on disability demonstrate the importance of attending closely to the experiences of individuals with disabilities in making decisions whether to use medical, psychological, or social interventions that may affect the person’s identity and alter subsequent experiences. Though each article focuses on the problems or merits of different types of interventions—cochlear implants, surrogate partner therapy (SPT), and growth attenuation—all of the articles draw the reader’s attention to the need to reconsider the medical model of disability and attend to the potentially corrective value of the social (or psychosocial) model of disability. The latter model of disability emphasizes the impact of prevailing social attitudes and institutions on the welfare of individuals with disabilities, while the former, with its tendency to pathologize deviations from typical species function, seems to provide a more “deterministic” and often myopic lens through which to view disability.

A major theme across these articles is the need to create or expand opportunities for people with disabilities. This is brought out in all three articles, but most explicitly in Mintz’s article, which defends the view that sexual functioning is an essential element of health, and as with health generally, allows an individual to avail himself/herself of the normal range of opportunities within society. For instance, in defending SPT against critics of the practice, Mintz points out that the goal of SPT is to teach people to form intimate relationships, not merely to engage in sex. The focus, therefore, is on an important element of living a distinctively human life. Focusing on a broader array of interests and opportunities, the Peace and Roy’s narrative about Roy’s severely disabled daughter, Sophie, demonstrates the tremendous benefits of adequate social support, vividly contrasting Roy and Sophie’s experience in Canada with the experience of Peace and others in the United States. Focusing specifically on deafness, Jones and Saladin advocate for a more informed decision making process that includes perspectives from the Deaf community, and more comprehensive social support for individuals deciding for themselves or their children whether to use cochlear implants.

Another overarching concern that emerges in this issue is the tendency to assume that the limitations of people with disabilities are more extensive than is actually the case. Non-disabled persons, including members of the medical community, draw unwarranted inferences from the presence of physical limitations to the existence of varied and more severe functional deficits. Jones and Saladin observe that, because deafness
sometimes appears alongside limitations in mental functioning, there is a tendency to erroneously conflate deafness with cognitive impairment. A related, equally problematic tendency is to assume that the presence of either physical or cognitive deviations from the norm somehow obliterate typical human desires or interests and so do not need to be considered in decisions about whether a person should undergo a particular medical intervention. As Peace and Roy’s article shows, this can lead to problematic actions in either direction. A radical intervention, such as growth attenuation, may be undertaken, or it may be assumed that a person with a disability lacks even the basic interest in continuing to live. Though approaching it differently (e.g., Jones and Saladin and Mintz emphasizing individual autonomy; Peace and Roy questioning the merits of at least one concept of autonomy), all of the authors in this special issue caution against rigid assumptions about the interests, desires, and present or future abilities of individuals with disabilities and encourage a healthy skepticism about the ability to adequately grasp the inner states of individuals’ with limited means of communication.

For example, it may be assumed that a person with a physical disability is [cognitively impaired and therefore] asexual. As McRuer and Mollow observe in their introductory chapter to *Sex and Disability*, “rarely are disabled people regarded as either desiring subjects or objects of desire…the sexuality of disabled people is typically depicted in terms of either tragic deficiency or freakish excess” (2012, 1). Such attitudes regarding sex and disability are not the sole source of objections to SPT. However, widespread assumptions about the abilities and interests of people with disabilities appear to have at least a background role in fueling debate, such as the one Mintz describes as erupting in France upon the release of the movie *Sessions*. Mintz’s defense of expanded legalization of SPT demonstrates his rejection of the prevailing narrative and its implications for people with disabilities.

Although the authors lodge legitimate criticisms of the medical model of disability and demonstrate the importance of promoting and expanding opportunities for people with disabilities through an appeal to the social model of disability, they do not dispense entirely with the concept of disability as a deviation from typical species functioning. Instead, echoing Morris, the authors in this issue collectively “reject the meanings that the non-disabled world attaches to disability” while continuing to embrace the core differences that are influential in shaping the identities of individuals with disabilities (1991, 16). It does not follow from this that people with disabilities either aspire to “be normal” or undergo life-altering interventions (e.g., growth attenuation, cochlear implants) that will significantly modify their way of interfacing with the environment and therefore their identities.

In their article, for example, Jones and Saladin defend the view that choosing cochlear implants for oneself or one’s child is a decision that should be informed by a clear grasp of whether a life as a deaf or Deaf person would be good for a particular individual. As Jones and Saladin point out, this depends on whether the person is likely to be burdened or empowered by their deafness. Peace and Roy’s skepticism about the medical community’s predictions regarding the future abilities of infants and children
with severe cognitive impairments raises some doubt about the ability predict whether deafness would ultimately be burdensome or empowering for a particular individual.

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References