

**Pursuing the *Vox Populi*
Responding to Commentaries on Stowe et al., Journal on
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We are delighted that our article provoked so many incisive commentaries; that was its driving purpose and is needed if the Vox Populi of the disability community is to participate in shaping the genetics era.

Throughout the article, we discuss the implications of human genetic research from the perspective of the "disability community." Yet, the term itself is, at best, a useful fiction with regard to the HGP implications. There is no single image attached to the fiction, no single voice of the disability community, as the emphasis of the various commentaries illustrates.

Stainton and Miceli/Steele sharpen our focus on the issues of pre-implantation genetic diagnosis and selective elimination of disability. Newell echoes many of these same concerns in cutting to the root issue of disability as created by concepts of normalcy. Giné adds a call for additional focus on identification and measurement of supports. Shalock shares Giné's concerns and proposes guidelines informed by disability ethics and quality of life standards. Rapley and Parmenter highlight the danger posed by a genetic age shaped by commercial interests and utilitarian philosophies. Rubin warns of complacency and the need to engage in both dialogue and action, to which Noonan adds a reminder of cultural differences and other challenges to an inclusive dialog and a unified perspective.

Significant differences exist among perspectives of individuals with disabilities, their families, and their advocates. There also are differences between the so-called disability community and the research community and its advocates. In our article, we highlighted what is arguably the most significant of these – the perspectives of those (disability rights advocates) who primarily seek equality and social change to address invidious treatment of individuals with disabilities and the perspectives of those (scientific advocates) who primarily seek to foster improved ways to diagnose and treat biological impairment.

These perspectives often conflict. Disability rights advocates claim that scientific advocates foster stigma in the form of perceptions of persons with disabilities as suffering from their disabilities. By contrast, scientific

advocates claim that disability rights advocates villainize their right to seek medical research and treatment that will improve their quality of life.

The battlegrounds for these conflicts involve economics, Rawlsian distributive justice, concepts of normalcy and dignity, and the rights to seek treatment that will improve quality of life and to refuse testing or treatment.

The victor in these battles is the same: those who wish to marginalize the disability voice in policy, practice, and society at large. The fragmentation of disability advocacy – by disability classification, by funding stream, and by differing interests and perspectives among persons with disabilities – only weakens the already "soft voice" of persons with disabilities and casts real doubt on whether the *Vox Populi* of disability community members will inform and help shape the genetic age. Yet, it is inadvisable not to heed the discourse that disability rights advocates and research rights advocates sponsor. The conundrum is not solved by suppression.

There is a two-fold answer to this conundrum. First, we must act on the significant areas of agreement that exist among disability community members. Foremost among these, as the article suggests and the comments reflect, is the important role that perceptions and attitudes about disability play, especially among policy makers, professionals, and the general public. One should not interpret our article as signifying that we ourselves disagree at all with the commentators. Indeed, we advocate building on these areas of agreement by fostering the intrinsic worth of all persons to respond to instrumental individualism (Parmenter), fostering inclusion (Giné, Stainton, Walsh), ensuring that the positive aspects of living with a disability are recognized (Miceli and Steele), the social, political, and commercial nature of science is explored (Newell, Rapley), and that the inherent right of persons to refuse testing and treatment is recognized.

So, one part of the answer to the conundrum is for members of the disability community to increase their efforts to educate the public, policy makers, and professionals – particularly genetic counsellors (Stainton) – to address the myths and misperceptions about life with a disability and genetic science and to foster recognition of the fundamental rights and dignity to which persons with disabilities are entitled. Guidelines, such as those proposed by Schalock, that demonstrate respect for persons with disabilities are particularly appealing. These are the areas in which the disability *Vox Populi* can already speak with a largely unified voice.

Second, we must increase our dialogue around genetics issues where no consensus exists either within or without the disability community. In doing

so, we must recognize the complexity of the issues and the value of all disability voices. We must examine the forest as well as the trees (Stainton) and delve deeply into the issues of normalcy (Newell) without falling prey to the argument that the disability rights perspective ignores real biological impairment – one that resonates with many members of the disability community as well as the general public.

We must ask difficult questions about personal autonomy in reproductive decision-making, such as "Can parents ethically select not to have a child with Tay Sachs disease?", "What about cystic fibrosis?", or "Does it matter if they already have a child with a disability?"; about what are and are not "normalizing" procedures, such as dietary changes for children with PKU, education, or assistive technology; about what are and are not inherently eugenic procedures, such as prenatal testing, pre-natal vitamins, or smoking and alcohol cessation programs targeting pregnant women; and about the definition of disability, such as "Is it defined purely by social reaction to impairment?", "Does impairment include disease or any differences in ability?", or "Does it include genetic susceptibilities?". These and other questions require continuous, informed, and passionate discussion. We simply have to embrace their complexities.

We referred to Orwell's *1984* to encapsulate the "Brave New World" that we are entering rather than to Huxley's work from which the term derives. We chose *1984* and the term "Brave New World" for the warning that even limited reference to each generally invokes – to what T.S. Elliot would have termed the "historic sense" of each. But perhaps a different Orwellian comparison is more appropriate. We refer, of course, to his *Animal Farm*. In *Animal Farm*, the Pigs take advantage of the division among the other animals – playing off the weakness of some and the ignorance of others – to twist an originally noble goal into a means to secure dominion.

The very term "disabled" invites power and dominance. The act of classification can permit mastery and servitude. And science itself can foster valuing or devaluing language and action, just as science can be shaped by valuing and devaluing language or action. The interplay of culture and science is two-sided. That's the point of our essay, and it is one that our commentators do not gainsay.

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