

**Exciting New Times Require us to Learn From our Past
Commentary on Stowe et al., *Journal on Developmental
Disabilities*, 13(2), 2007**

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As we become swept up in the feverishly exciting pace of advances in our understanding of genetics – of how it can tell us so much about life on this planet, of how evolution has taken place, of how each one of us carries within us genetic information that can trace our own ancestors, of how diseases are caused, of how diseases and disorders can be identified and treated, and of how our lives can be improved and prolonged – we only have to ask ourselves what more can it do and wait for the answers.

In these giddy times, Stowe, Turnbull, Schrandt, & Rack (this issue) sound a cautionary note that would be good for us to heed. Not too long ago, our society was similarly seduced by what science had to offer and our scientific advances in the 20th Century changed the way we lived and thought – much of it for the better; however, at times, breaking our ties with centuries and millennia of tradition that affected social and ecological harmony and homeostasis. We are still reeling from the social and environmental changes and trying to come to terms with where we are now and how to deal with the outcomes and consequences. Our understanding of the physics of the atom is perhaps the most global, exciting, yet disturbing of the advances. Although it has helped us to fathom the depths of the universe and the workings of life on this planet, it also gave us the atomic bomb that wrought such destruction and has hung as a threat to the annihilation of life on this planet since then. On a more familiar and relevant note, the so-called science and practice of eugenics reached its horrifyingly nightmarish peak at the end of the first half of the 20th century in countries and in cultures that we had come to believe were the most sophisticated and advanced in the world at that time. Closer to home, we have all become aware of the scientific experiments with men who suffered from syphilis in Tuskegee, Alabama, where the scientific method and goals of the science overpowered the sense of human suffering and indignity.

It is fortunate that we as a society have a complex organization and, within it, systems of checks and balances, laws and processes that hold at their core a philosophy and set of values about whom we are and our responsibilities to each other and to our environment. These enable us to avoid making big mistakes and certainly not to make the same mistakes again. Since the Magna Carta, our societies have built into them a sense of equity and equality that has resulted in the constitutions of the United States and other countries opportunities to question, and to put into place constitutional

amendments and laws that have been designed to protect us and our vulnerable fellow citizens from abuses. Our responsible academic institutions have developed Human Rights Committees and Institutional Review Boards that regulate and monitor scientific studies that involve human subjects. But we must not be complacent and feel that we have all systems in place to prevent any future injustices from being perpetrated.

Stowe et al. remind us of the circumstances of history that had led to the abuses and indignities of individuals whose own voices are relatively soft in our society and how the creeping tide of advances can have a significant impact on the lives of the most vulnerable members of our society without even realizing it until it is too late. As I see it, their concern is based on the history of similar advances and as they point out, although we have developed systems to deal with what we already know, and that these systems can help us with our ability to deal with similar situations in the future, there are two factors that deserve special mention. One is that new advances evince new challenges that we should anticipate and confront. This is the practical aspect of the paper. The second is the more concerning and insidious because it deals with the human element and societal attitudes that can readily direct and govern social behaviors and policies that affect everyone. They remind us that it was not long ago that there were hard fought and hard won struggles for human rights, equality and dignity for vulnerable populations that included people belonging to certain racial and ethnic groups, the poor, children and adults with intellectual and developmental disabilities. They wake us up to the potential that our advances in the sciences in general, and the application of advances in genetics in particular, can have on these very populations, and that not only do we need to be aware of it, but more importantly we need to be talking about it and developing policies and processes to make sure we do not make the same mistake again!

References

- Stowe, M. J., Turnbull, H. R., Schrandt, S., & Rack, J. (2006). Looking to the future: Intellectual and developmental disabilities in the genetics era. *Journal on Developmental Disabilities*, 13(1), 1-64.

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