Cultural Influences on the Future
Commentary on Stowe et al., Journal on Developmental Disabilities, 13(2), 2007

Patricia Noonan Walsh

For non-experts, genetics has a rather brief history. It first revealed itself in the reproductive lives of fruit flies, busily transmitting traits to subsequent generations according to design. DNA was an elegant double helix famously mapped in post-war England, more recently familiar as a tell-tale trace in crime scene investigations glamourized for popular television. Ambitious projects such as the country-wide survey of the genetic inheritance of all Icelanders swelled a sea-change in how genetics is perceived: a scientific, social, and political phenomenon with potentially profound impact on human life. As genetics continues to emerge as the defining feature of a global era, even non-experts find themselves engaged.

Stowe, Turnbull, Schrandt and Rack (this issue) now urge leaders in the disability field to take into account policy, history, and ethics in shaping a vision of how research in the genetics era might influence the lives of people with disabilities and their families. Three aspects of this future challenge merit comment here: how the impact of genetics research may differ across cultures, how practical matters such as linking research with practice or policy might be resolved, and how the authors' own recommendations might be applied.

Cultural Influences

Although it is often assumed that the deepest concerns and goals of people with disabilities and their families are the same the world around, nonetheless individuals are born, grow, and reach maturity in a given culture. Indeed, the Standard Rules on the Equalization of Opportunities for People with Disabilities (United Nations, 1994) recognize the rights of persons with disabilities to be members of their own culture and take part in its life.

The authors write from the United States, and it is safe to assume that the first waves of the future will reach the shores of this very large, very wealthy country earlier than most. Knowledge about the experiences of people with disabilities in many of the world's low- and middle-income countries is

incomplete; we understand much less about how these countries will manage knowledge about genetics. But it is unlikely that cultures will regard information yielded by genetics research in a way that will not vary. Nor is the plea for any sort of scientific information itself culture free. Already, technological advances make it possible to predict characteristics of children as yet unborn. In the U.K., press coverage at the time of writing highlighted the rise in terminations of pregnancies where prenatal scans reveal a fetus with clubfoot or other physical anomaly that elsewhere might be viewed as easily treatable.

When heritable conditions become charted more accurately, difficult questions will proliferate: for example, will prospective parents become obliged to seek such information, and, if findings so indicate, what pressures will be brought to bear on them? Such questions probe the very core of the way we think about people who have disabilities. While the questions are profoundly human, the responses are likely to be embedded in traditional beliefs and timeworn approaches that reflect a specific culture.

Practical Matters

In genetics as elsewhere, smooth sailing depends on how well we join up research, policy, and practice. But experience tells us that mismatches are often the rule. Leadership in genetic research is not always matched by expertise in clinical genetics. Research findings do not necessarily give rise to counselling or other comprehensive services for individuals and families whose life experiences may be deeply involved with heritable conditions.

Practice and research, in turn, may not be linked with policy. Mention of genetics or genetic counselling was absent from Ireland's Disability Bill, published in September 2005 (Government of Ireland, 2005).

From time to time, clinical research generates heat, not light. In the past few years it came to national attention that some Irish hospitals had kept infants' post-mortem organ and tissue samples for scientific investigation without, it was alleged, specifically securing informed consent from parents. The resulting wave of dismay and anger gave rise to widely-publicized tribunals and perhaps spilled over into a wider arena where scientific endeavour at this level is viewed with suspicion.

These apparent gaps mark the landscape in a small, prosperous European country with a population of 4 million persons. It may be assumed that other countries, too, have not made seamless progress in how they manage

genetics research, inform policy with scientific findings, or provide real supports to real people with disabilities and their families.

Recommendations

What advice is sound for those embarking on a voyage through the new era? One recommendation is to endorse a unified disability perspective as a potential strength. Here the authors prudently outline the potential tensions between two forces: one advancing interests of people with disabilities and their families in response to social or political trends, and the second pursuing scientific progress.

But in the pursuit of unity, other dilemmas will arise. Will the voices of advocates who decry any attempt to identify, enumerate, or categorize persons with disabilities be heard? If we hold fast to the principle of self-determination, will people with disabilities be supported in electing not to avail themselves of genetic services? If scarce resources for the disability sector are rationed, must constituents compete for what they need to promote lifelong good health and well-being?

A second, but related, recommendation is to offer appropriate education to people with disabilities and their families to ensure that they have access to, and can act upon, any genetics information that is useful to them in the course of their lives. This is particularly valuable when identifying a genetic trait helps to target optimal intervention and thus enhance an individual's quality of life. The challenge here is to place in harmony the expert knowledge about genetics held by professionals and the lived experiences of people with disabilities. A first step is to heighten understanding on both sides.

The Future

The future promises a voyage through unfamiliar territory. Happily, the tried and true strategies of informed advocacy, sound ethics, linking research with policy and practice, and promoting self-determination are in hand and lend themselves to managing the new challenges posed by genetics research. Doing so will offer a fresh opportunity for public dialogue about the place of people with disabilities in the world and how they are perceived, valued, and supported where they live.

Few of us will gain insights to match those of Mendel, Crick, or Watson. But all of us will live in a world changed by new knowledge, along with family

members, friends, and neighbours whose lives will likewise be changed. Recall that Miranda – reared by a single parent, home-schooled, madly in love, and soon to be a migrant – exclaims in wonder at the people in her brave new world – not at its governance or social policies.

References

Government of Ireland. (2005). *Disability Bill.* Retrieved August 19, 2006, from http://www.oireachtas.ie.

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.

United Nations. (1994). *Standard rules on the equalization of opportunities for people with disabilities.* New York: Author.

Correspondence

Patricia Noonan Walsh
patricia.walsh@ucd.ie

Centre for Disability Studies, School of Psychology
Newman Building D-005
University College Dublin
Belfield
Dublin 4
Ireland