

**New Challenges, Better Opportunities and Outcomes in
the Coming Decades**
**Commentary on Stowe et al., *Journal on Developmental
Disabilities*, 13(2), 2007**

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First, I would like to express my recognition and gratitude for the work presented by M. Stowe, R. Turnbull, S. Schrandt, and J. Rack (this issue). From my point of view – and taking into account the impact this work may have in my country (Spain) – this is an appropriate, exceptional, relevant and brave work due to its content, richness of analysis, and method used.

At present, I think it is particularly appropriate and necessary to start a public dialogue on the implications of human genetic research for people with disabilities, not restricted to the field of university research, but with the aim of extending it to society and incorporating the voice of people with intellectual disabilities and their families. Besides, most questions under debate affect many situations and needs in other sectors of society.

The novelty of this article, due to the authors' approach, the aspects dealt with, and the conclusions expressed, makes it also exceptional. Indeed, there are not many works focussing on the implications of human genetic research on the quality of life of people with disabilities – not in my country either. I would like particularly to refer to the authors' call to participate proactively in a public dialogue about these issues.

Undoubtedly, this is also a relevant issue, both for people with disabilities and their families and for society in general; the conclusions of the study account for this. On the one hand, society cannot disregard the consequences that human genetic research implies for all of us, with regard to both its many possibilities and clear risks (e.g., possible genetic discrimination). On the other hand, the work's relevance also derives from its potential impact on the rights and services for people with disabilities and their families, as well as from the recognition of the impact of genetic research and technologies on people's values and attitudes.

Finally, we can say that this is a brave work. The debate about the social impact of human genetic research is subject to pressure by political, economic, media and other groups that aim at imposing their criteria. The authors' analysis is not limited to political correctness, but expresses their honest opinion concerning both possibilities and risks, urging all involved

sectors to participate, as well as the need to advocate for the perspective of people with disabilities and their families with the purpose that this becomes a positive contribution to a higher quality life.

I would like to end this contribution with an attempt to answer the authors' question posed at the beginning of their article about what factors may affect the life of people with intellectual disabilities and their families in the coming decades. From the perspective of my country, I would like to point to the following factors. The first one is a real concern about the improvement in the quality of life of people with disabilities and their families by means of improving services and participation. In this sense, we have to refer to the "real" support that families need to face daily demands. This is a concern of both the service sectors involved and university research. The second factor is the will to advance in identifying and measuring supports needed by people in various life and community contexts in order to obtain the needed funding. The third one is the improvement in professional training and, particularly, teacher training in the horizon of a school for all; only inclusive education will contribute to a society that is more respectful of individual differences and more committed to providing work and life opportunities. Finally, there is a need to advance both services and research in the areas of diagnosis and attention given to people who, together with an intellectual disability, also have some emotional disorder.

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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