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Autism Genome Project

Integrated GE³LS Research

The communication of genomics research results to research participants

GE³LS Project Leaders

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Summary

Genomic research on the autism spectrum disorders (ASD) raises a number of social and ethical issues. These include issues in human subjects research more generally, and in the ethics of research on a medically and social complex child-onset disorder more specifically.

Most of our research has concerned the issue of communicating genetic research results to research participants. Recent commentaries argue that researchers bear an obligation to report genetic research findings to study participants. Others contend that while the principles of respect for persons, reciprocity, and beneficence indeed apply to the research context, they may neither be well served if results are disclosed nor denied if they are not disclosed. This issue is particularly challenging in the context of autism genomics, given the intensity of the relationship between researchers and the participant community, the complexity of the scientific information generated, and the multifaceted ways in which this information may be interpreted and used by research participants and families. The communication of genetic research results also bears on issues of health and social service delivery, and the extent to which research can or should serve a compensatory function.

We have pursued research on these issues through a review of relevant sub-national, national and supra-national policy guidance, and a set of qualitative interviews with researchers and research participants. We are currently mounting a survey of ASD genomics researchers using an experimental design, to understand the myriad factors influencing professional judgments regarding the disclosure of genetic research results.

Related publications

Miller, F.A.; Giacomini, M.; Ahern, C.; Robert, J.S.; de Laat, S. 2008. When research seems like clinical care: A qualitative study of the communication of cancer genetic research results. *BMC Medical Ethics*, Vol 9: 4.

Miller, F.A.; Giacomini, M.; Robert, J.S.; Christensen, R. 2008. Duty to disclose what? Querying the putative obligation to return research results to participants. *Journal of Medical Ethics*, Vol 34: 210-213.