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Children in the moral community.
Predictive genetic testing of children for
adult onset diseases: some ethical
implications

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Abstract

Where are children situated in the moral community? Are children special from a moral point of view? Does children's youth and vulnerability say anything significant about how we ought to treat them? These questions seek to articulate and clarify the moral status of children by considering what is required to be the beneficiary of moral standing, and furthermore, the ways in which we, as moral agents, are obliged to treat them. The ways in which we answer these questions has significant implications for children, particularly in the area of predictive genetic testing.

My thesis is divided into two sections. In the first section I examine the moral status of children within the moral community and the obligations owed to them from parents and society. This is important for a number of significant reasons: Firstly, within the literature children are often portrayed as smaller, less competent versions of adults, yet they are clearly different to adults in many significant ways. Secondly, whilst we claim that children are precious and deserve to be protected from harm, we continue to abuse, neglect, and treat them with indifference in our families and communities. Finally, children grow up and assume their place in the world. This suggests that their moral status changes over time. If children are important members of the moral community as I suggest they are, then we ought to be clear about what their moral status obliges of us as adults. This has crucial implications for children in the area of predictive genetic testing for adult onset diseases.

In section two I build on the ethical framework and conclusions reached in the first section and examine the specific question of whether we ought to genetically test children for adult onset diseases. All international genetic service provider guidelines and professional genetic societies do not recommend testing currently healthy, asymptomatic children for such diseases. I examine their positions and consider the arguments not to test children for adult onset diseases.

Dedication

I would like to dedicate my thesis to my father, Alan Robert Gurr, and to all children and their families living with an adult onset disorder.

Preface and Acknowledgments

Versions of some chapters of Section Two have been published:

Malpas, P. J. (2005a). Predictive genetic testing in children and respect for autonomy. *International Journal of Children's Rights*, 13, 251-263. This paper appears as Chapter Two.

Malpas, P. J. (2005b). The right to remain in ignorance about genetic information – can such a right be defended in the name of autonomy? *New Zealand Medical Journal*, 118(122), 1611-1619. This paper appears as Chapter One.

Malpas, P. J. (2006). Telling at-risk, asymptomatic children an adult onset disease exists within the family but refusing to test them for it. Why not test? *Journal of Medical Ethics*, 32(11), 639-642. This paper appears as Chapter Five.

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