

The Ethics of Screening in Health Care and Medicine

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Niklas Juth · Christian Munthe

The Ethics of Screening in Health Care and Medicine

Serving Society or Serving the Patient?

 Springer

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Acknowledgements

This book is the result of work carried out over a period of at least ten years, probably longer. The awareness of the importance and variety of ethically relevant ways in which screening programmes differ from other ways of organising the offering and use of medical testing methods has been growing gradually in the context of both of our past research on the ethics of, e.g., genetic testing, prenatal diagnosis, reproductive medicine and public health. The actual idea of writing a book specifically about the ethics of screening was, however, a slightly more recent one, and in a way it came about due to a mistake. In late 2004, we were asked by the editors to contribute a chapter on the ethics of screening to the 2nd edition of the massive collection *Principles of Health Care Ethics*¹ (a classic advanced reader and reference work in the fields of bioethics and general health care as well as medical ethics). Flattered, we accepted and got to work without checking properly what was actually expected of us, with the result that we submitted a manuscript of about 22,000 words and were harshly told to cut it down to about 5000 (which we did, of course²) with the off-hand remark that we could always use the longer text as the basis for a book. Looking back, we are extremely grateful to Richard Ashcroft, Angus Dawson, Heather Draper and John McMillan – both for steering us onto this path in the first place and for stimulating our motivation for our subsequent work by applying strict editorial discipline to our tendency of enthusiastically getting ahead of ourselves. We are equally grateful to David Weisstub, who, over a nice cup of coffee in Stockholm autumn 2009, took an interest in the manuscript and suggested we send it to Springer and the International Library of Ethics, Law, and the New Medicine Series.

¹ Ashcroft et al. (2007).

² Juth and Munthe (2007).

Research – even in ethics – and writing furthermore requires time and resources and we have been lucky to have been awarded that in the context of a series of projects where themes appearing in this book have been overlapping in various ways. The Swedish Ethics in Health Care Programme generously funded the project *Presymptomatic Testing and Genetic Counselling: Goals and Ethics for Clinical Practice, Caring and Education* (2000–2008), as did the European Commission of *European Public Health Ethics Network (EuroPHEN)* (2002–2006) and, later, the Swedish Government and the University of Gothenburg funded projects and collaborations from 2006 that eventually has become the *University of Gothenburg Centre for Person Centred Care*. Karolinska institute generously funded more time for research for one of the authors, funds without this book would not have been completed.

Already when working on the original chapter, we received valuable assistance of several people, besides the above-mentioned editorial team, and this aspect of the work has, of course, expanded as we set out to realise the vision of a book. Ethics researchers are at heart theoretical analysts, so when ethics is applied to concrete areas of practice one becomes extremely dependent on experienced and wise guides and door openers with regard to how this practice actually works and reliable information and pedagogical explanations of the many scientific aspects that are relevant. Accordingly we would like to thank The-Hung Bui (senior clinical consultant of clinical genetics, prenatal diagnosis and foetal medicine at Karolinska Institute), Ulrika von Döbeln (head of the Swedish neonatal screening programme, Karolinska Institute), Karl-Henrik Gustavson and Jan Wahlström (retired professors of clinical genetics at Uppsala University and the University of Gothenburg, respectively), Darren Shickle (professor of public health at the University of Leeds), Erik Björck (chief of medicine in clinical genetics, Karolinska institute) and Amy J Hoffman (project manager of the Newborn Screening Translational Research Network at the American College of Medical Genetics & ACMG Foundation), as well as the working group on bioethics and legal issues of the same institution. Partly in the context of the projects mentioned above, we have received further assistance in the context of discussions by numerous colleagues in our own field, where we (besides the mentioned editorial team) accidentally and regretfully happen to remember only Henrik Ahlenius, Bengt Brülde, Daniela Cutas, Gert Helgesson, Göran Hermerén, Søren Holm, Matti Häryry, Niels Lynöe, Lars Sandman, Manne Sjöstrand, Tuija Takala, and Maja Wessel. Two reviewers

for Springer – one of which, Marcel Verweij, chose to waive anonymity – took their job admirably serious and provided a great number of perspectives, critical points and pieces of information without which this book would have been much inferior to the present version.

Needless to say, none of the people or organisations mentioned are to be held accountable for any of our remaining mistakes and flaws.

Contents

1	Introduction	1
1.1	The Wilson and Jungner Criteria	3
1.2	Plan and Point of the Book	5
1.3	The Concept of Screening	6
2	Why Screening?	13
2.1	Screening, Treatment and Prevention: Preliminary Remarks	14
2.2	Health: Life and Well-Being	18
2.2.1	Health and Counselling	19
2.2.2	The Good of People and of the Population	20
2.3	Autonomy	22
2.3.1	Respecting and Promoting Autonomy	23
2.3.2	Promoting and Respecting Autonomy Through Screening	25
2.4	Justice	27
2.5	Summary	29
3	Screening – What, When and Whom?	31
3.1	Diseases and Groups	31
3.1.1	Prenatal Screening	33
3.1.2	Neonatal Screening	42
3.1.3	Child and Adolescent Screening	53
3.1.4	Adult Screening	58
3.2	Investigation, Testing and Analysis	60
3.2.1	Safety	61
3.2.2	Validity	63
3.2.3	Predictive Value	67
3.3	Treatments	72
3.3.1	Abortion as a Treatment	73
3.3.2	Counselling as a Treatment	75
3.4	Summary	78

4	Screening – How?	81
4.1	Informed Consent	82
4.2	Counselling	87
4.2.1	Genetic Counselling as a Template	88
4.2.2	Expansion: Shared Decision Making	93
4.3	Funding and Participation	95
4.4	Summary	97
5	Case Studies	99
5.1	Non-invasive Prenatal Diagnosis	100
5.2	Neonatal Screening for Fragile X	108
5.3	Mammography Screening	114
5.4	PSA Screening for Prostate Cancer	122
6	Serving Society or Serving the Patient?	127
6.1	Summary of the Analysis so Far	127
6.2	The Public Health – Health Care Tension Area	130
6.3	The Relevance of a Social Science Perspective	132
6.4	An Institutional Approach to Health-Related Ethics: A Sketch	135
6.5	Applying the Institutional Approach: Three Cases	137
6.5.1	Institutions, Functions and Ethics: Prenatal Care vs. Communicable Disease	138
6.5.2	Direct to Consumer Genetic Testing: The Limits of Context Relativity	141
6.5.3	Screening and Justice: When to Spend Health Care Resources on Screening	147
6.6	Revisiting the Wilson and Jungner Criteria for Screening	149
6.7	Closing	157
	References	165
	Index	175