

Genetic screening and democracy: lessons from debating genetic screening criteria in the Netherlands

Carla Geertruida van El · Toine Pieters ·
Martina Cornel

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Abstract Recent decades have witnessed increasing possibilities for genetic testing and screening. In clinical genetics, the doctor's office defined a secluded space for discussion of sensitive reproductive options in cases of elevated risk for genetic disorders in individuals or their offspring. When prenatal screening for all pregnant women became conceivable, the potential increase in scale made social and ethical concerns relevant for the whole of society. Whereas genetic testing in clinical genetic practice was widely accepted, prenatal screening at a population level met with unease. Concerns were raised regarding social pressure to screen: the

sum of individual choice might result in a 'collective eugenics'. The government's involvement also raised suspicion: actively offering screening evoked associations with eugenic population policies from the first half of the 20th century. By reconstructing elements of policy and public debate on prenatal screening in the Netherlands from the past 30 years, this article discusses how the government has gradually changed its role in balancing the interest of the individual and the collective on genetic reproductive issues. Against a background of increasing knowledge about and demand for prenatal screening among the population, governmental policy changed from focusing on protection by banning screening toward facilitating screening in a careful and ethically sound way by providing adequate information, decision aids and quality assessment instruments. In the meanwhile, invigorating democracy in public debate may entail discussing concepts of 'the good life' in relation to living with or without impairments and dealing with genetic information about oneself or one's offspring.

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C. G. van El (✉) · M. Cornel
Section Community Genetics, Department of Clinical Genetics
and EMGO Institute for Health and Care Research,
VU University Medical Center,
Van der Boechorststraat 7,
1081 BT Amsterdam, The Netherlands
e-mail: cg.vanel@vumc.nl

T. Pieters
Department of Medical Humanities,
VU University Medical Center,
Van der Boechorststraat 7,
1081 BT Amsterdam, The Netherlands

C. G. van El · M. Cornel
Centre for Society and Genomics, Radboud University Nijmegen,
Nijmegen, The Netherlands

M. Cornel
Centre for Medical Systems Biology,
Leiden University Medical Center,
Leiden, The Netherlands

T. Pieters
Descartes Centre for the History of the Sciences,
Utrecht University,
Utrecht, The Netherlands

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Introduction

In the years 2010 and 2011, revolutionary steps in noninvasive prenatal diagnosis (NIPD) were reported. It is now possible to sequence cell-free foetal DNA in maternal serum to detect Down syndrome, and in principle, it should also be possible to detect many more genetic disorders (Chiu et al. 2011; Lo et al. 2010; Fan and Quake 2010). Although the first proof-of-principle NIPD tests are especially targeted at women who have high risk of carrying a foetus with Down syndrome, it is envisaged that in the near future such tests would become available for all

pregnant women. The uptake of diagnostic testing is currently partly constrained because of the risk of iatrogenic abortion induced by invasive chorionic villus sampling or amniotic fluid test. To date serum screening can only assess risk for neural tube defects and Down syndrome. If these risk assessment tests were replaced by highly reliable noninvasive tests more women might opt for testing. Would NIPD testing become routinely available, this would mean a new phase in a long process of increasing possibilities to detect foetal abnormalities in pregnant women that started in the 1950s.

Whenever new technological options, such as genetic tests, become available often political and public debates are called for to discuss the social and ethical ramifications. The advent of NIPD led a commentator in the journal *Nature* to state: ‘That possibility challenges all societies to decide for which ends and by what means they want such tests to be used’ (Greely 2011). Similar debates took place in earlier phases of introducing and expanding prenatal genetic testing and screening. In this article, we will reflect on the dynamics of the discussion on these issues in the Netherlands during the past 30 years. Whereas other authors have written on prenatal screening in the Netherlands (Stermerding and van Berkel 2001; Toom and van Berkel 2003; Popkema and Harbers 2005; Meijer et al. 2010) and we have outlined these discussions before (van El et al. 2010a),¹ the focus of this account will be on the tension between individual considerations versus collective ramifications regarding certain technologies. Whereas reproduction is key to any society, balancing the tension between the interest of the individual and the collective regarding genetic reproductive issues is a delicate issue in modern democracies and a challenge for governmental policy making. The use or misuse of genetics by individuals or institutions in the first half of the previous century still sets the background of present-day arguments.² The Netherlands is well-suited for a case study to explore balancing this tension. The country has an up-to-date health care system providing adequate basic services to the whole population while enabling the provision of extra services of personal preference; thereby, there is a mix of continental and American health care systems. The Dutch public domain has elements of Christian moral principles as well as social–democratic and more liberal influences, necessitating dialogue and seeking consensus. This public domain operates at a relative distance from the government. Coalition governments try to respect the views of their rank and file supporters as well as integrate various standpoints into generally accepted policy.

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² The choice for this focus was inspired by the Genetics and Democracy series organised in Lund, Sweden, where part of this paper was presented on October 5, 2009.

For our research, we interviewed stakeholders, organised a so-called witness seminar with 20 stakeholders who had been active in genetic testing or screening and/or related policy issues (van El et al. 2010b), collected archival material, studied the clippings archive of VU University and collected articles in Dutch medical journals on the subject of genetic testing and screening.

We will briefly discuss three occasions during the second half of the 1980s on which genetic testing and screening for reproductive issues became subject of wider attention, and were discussed in medical journals, newspapers and/or television programmes. In addition, we will discuss new regulation during the 1990s, and changes in policy, as well as public and professional views during the 2000s.

From genetic testing to genetic screening

The recent decades have witnessed increasing possibilities for genetic testing and screening. In the Netherlands, since the 1970s, individuals and their family members could obtain genetic counselling for their own risk or diagnosis of a serious genetic disorder or that of their offspring. At this time, a foundation was laid for what was later to become the specialty of clinical genetics (Nelis 1998). Consensus on the standards of the developing profession was formulated by a relatively small group of medical professionals and experts of the Health Council of the Netherlands (1977; 1980) and was supported by representatives of emerging patient organisations. In the intimacy of the consultation room, a secluded space was defined, where doctors and patients could discuss sensitive reproductive options in case of an elevated risk for genetic or congenital disorders.

During the 1980s, it became increasingly clear that new techniques might enable mass screening of pregnant women. Maternal serum screening tests were developed to detect neural tube defects, and a few years later, Down syndrome, in a foetus. This potential increase of scale meant that discussions on reproductive options were no longer confined to the secluded space of a doctor–patient relationship, but that prenatal testing and screening had become relevant issues for the whole society.

Discussing genetic testing and screening for reproductive issues

Better than God

In the Netherlands, the public awareness of developments in genetic research and testing was greatly influenced by a documentary series, *Better than God*, which appeared on television in 1987. The series discussed ongoing develop-

ments in genetic research and testing, and questioned whether handicapped people would still be welcome in future society. The series was discussed in newspapers, the director, Wim Kayzer, was interviewed and the connection between modern genetics and eugenic practices during the Second World War was readily made by him and journalists (e.g. Pols 1987).

In this climate of increased awareness and anxiety about developments in genetics, two reports on reproductive issues appeared that stirred political and public discussion setting the stage for the subsequent policies in the 1990s.

Prevention of hereditary and congenital anomalies

In December 1987, the Department of Health of the Netherlands published a report on the prevention of hereditary and congenital anomalies (Parliamentary documentation 1987–1988a). The department wished to formulate a comprehensive prevention policy by integrating knowledge of various forms of risk for the mother and the foetus. These ranged from lifestyle issues (such as diet and the teratogenic effects of substances such as alcohol, tobacco and medicines), to infectious diseases. In doing so, the department also responded to the World Health Organization (WHO)'s initiative 'Health for all by the year 2000' (WHO 1981) by calling upon national governments to reduce morbidity and mortality. In an effort to be comprehensive, the Department of Health report included a section on the use of genetic services. Genetic counselling was mentioned as one of several measures to reduce morbidity and mortality, and abortion of an affected foetus was circumscribed as a form of 'secondary prevention'. Clinical genetic centres would enable parents to enact 'responsible parenthood'. The report stated that people should decide for themselves what they meant by that term, its meaning was not further elaborated. However, the term was used in a section in which the societal cost or burden was also mentioned in relation to 'optimizing the chance of a good outcome of reproductive behaviour' (Parliamentary documentation 1987–1988a, 34–35). This might have been perceived as a governmental viewpoint favouring abortion as a cost-effective option.

The Parliament issued a call for reactions, after which they received responses from among others the patient organisation, as well as the professional organisation for clinical geneticists. Several newspapers and magazines covered the reactions to the report and the subsequent debate in Parliament. An important objection to the report for members of Parliament, clinical geneticists, journalists and an ethicist, concerned the terminology, as genetic services were associated with the notion of 'responsible parenthood', and 'optimizing the outcome of reproductive behaviour'. Interestingly, in the 1970s some of the same terms had been used without stirring controversy, such as

the term 'responsible parenthood'. The fact that genetic counselling was placed more explicitly under the heading of prevention policy, as well as raised awareness due to the documentary series, may explain the difference in response (van El et al. 2007, 2010a,b). In addition, the suggested aim of genetic counselling to reduce morbidity and mortality raised criticism. In genetic counselling, it is essential that patients be adequately informed so they can choose for themselves (informed decision making) whether or not to test and consider aborting an affected foetus in accordance with their own values and personal circumstances. Although reduction of the number of children born with a handicap may be an effect of genetic counselling, it is clearly not its aim, as was argued by an ethicist and secretary of the Health Council (De Wert and Engel 1988). Unintentionally, the impression had been raised that the government wanted to use genetic services to improve public health and reduce the costs of health care through preventive abortion of foetuses with severe handicaps. Members of Parliament and journalists wondered whether the government might be considering eugenic policies, and were concerned that people should still have the right not to be tested (Reformatorsch Dagblad 1988). In May 1988, the Minister and State Secretary of Health reassured the members of the Parliamentary Standing Committee on Health that there was no need to be concerned about the government's policy on prenatal testing and the position of handicapped people in Dutch society. The birth of a handicapped child would never be regarded as a case of failed prevention (Parliamentary documentation 1987–1988b).

The arguments in the public debate show that it was deemed problematic to subsume prenatal testing or screening and abortion under the heading of a prevention policy. A more careful policy was suggested to accommodate the specific sensitivities and requirements for various kinds of screening (Parliamentary documentation 1987–1988c). As a consequence of these discussions in governmental documents, more attention was given to terminology. Ethicists at the Ministry of Health became more closely involved in preparing policy documents.

Prenatal screening

In the beginning of the 1980s, the Health Council of the Netherlands was asked to report on the possibilities for prenatal screening. Screening tests had become available to measure the level of alpha foetoprotein in maternal blood as an estimate of the risk of the foetus having a neural tube defect. By the end of 1988, the Health Council of the Netherlands (1988) published a report advising the government to start a pilot programme for serum screening. However, the advice was not unanimous. An influential

geneticist at the time, Hans Galjaard, opposed the idea. He was the first chairman of the committee preparing the report, but stepped aside and published a minority standpoint at the end of the report (Health Council of the Netherlands 1988). One of his concerns was that the decentralised organisation of prenatal care in the Netherlands, mostly in the hands of midwives in primary care, left little time for retesting and follow-up after the first screening test in the sixteenth week of pregnancy. He also considered the bad test characteristics as problematic as false positive outcomes could cause unnecessary anxiety in pregnant women. Another issue that was brought up by him on various occasions was the fact that the risk assessment of genetic screening tests did not meet the standards of prenatal diagnosis. He was concerned that the public trust in genetic counselling and prenatal diagnosis—something that he had carefully helped to establish in the previous years—would be undermined (van El et al. 2010a,b).

In 1989, the Dutch government decided not to implement maternal serum screening for neural tube defects (Parliamentary documentation 1989–1990a). The decision was based on the WHO criteria written by Wilson and Jungner (1968). The test characteristics were found to be inadequate; there were too many false positives and false negatives. Since there was no treatment available, the criterion that only treatable disorders should be screened was not met. The test was considered to be unacceptable for the Dutch population. In a case of a positive test result, further invasive testing might cause an iatrogenic abortion. This was an ethical limit the government did not want to cross. Furthermore, psychological strain and medicalisation were mentioned as casting shadows over the ‘joyful period of pregnancy’. The government explicitly mentioned its concern that pressure from health care workers or public opinion might constrain the option of not taking a test. The government’s involvement might exert an ‘important influence’ in that respect (Parliamentary Documentation 1989–1990a). In Parliament, all parties from the left to right wing, including parties representing Christian denominations supported the government’s decision not to implement screening (Parliamentary Documentation 1989–1990b).

Dutch obstetric health care professionals were divided concerning the screening test. In the north of the Netherlands, screening had been offered on a small scale on a research basis. Obstetricians in that area had expected to continue or expand that practice. In 1990, at an obstetric conference to which foreign experts had been invited, pleas were made regarding serum screening (Mantingh et al. 1991). In the Dutch Journal for Midwives, the subject was heavily debated. The professional organisation, the Dutch Society of Obstetrics and Gynaecology, decided not to support serum screening.

Patient organisations were also divided. The Council for Handicapped People (Gehandicaptenraad) did not favour prenatal genetic screening, but the patient organisation for children with spastic disorders, BOSK, which included a group of parents of children with neural tube defects, was interested in the test, in principle.

Meanwhile, it had become clear that the test for neural tube defects could also be used to assess the risk for Down syndrome, namely by detecting low levels of alpha fetoprotein. A new round of governmental enquiry and requests for research began. In 1992, the Ethical Committee of the Department of Health advising on research applications (KEMO) was asked to consult on a project of the obstetricians in the northern and central regions of the Netherlands to offer screening for neural tube defects and Down syndrome and study the ethical and psychological aspects of such screening. KEMO had no ethical objections to this type of research. However, it mentioned that this might actually not be seen as population screening in the sense of an offer without a prior medical condition. Since the women were pregnant they were already receiving medical care. Furthermore, it was suggested that women might be informed about the test so they could make their own decision about it; thus reducing pressure to take the test (KEMO 1992). The same point of view was voiced by the parents’ organisation BOSK (BOSK 1992). The organisation wanted women of all ages to be informed about the test so they could decide for themselves. However, BOSK was concerned informed consent would not be guaranteed in case screening would be offered as part of a population screening programme; the free choice not to opt for abortion might be constrained through societal pressure. As we will discuss below, this distinction between offering and informing would become important in the next decade. The Minister, however, decided not to implement serum screening for Down syndrome in the early 1990s.

Testing for reproductive issues versus population screening

The discussion on serum screening should be seen in the light of previous developments during the 1980s. As became clear in the discussions about the departmental report on the prevention of hereditary and congenital anomalies (Parliamentary documentation 1987–1988a), there was a strong consensus for government to keep its distance from prenatal genetic testing. In clinical genetic practice in the Netherlands, parental autonomy had been firmly established. It appeared that by then a ‘field of argumentation’ had developed regarding genetic testing for sensitive reproductive options. On the other hand, quite another field of argumentation had formed concerning

population screening. There was consensus at the time that the instrument of population screening should be solely offered to improve public health if used for treatable disorders with an available early intervention. In short: no treatment, no screening. In this field of argumentation, the government should play an active role.

Prenatal screening did not fit either of these two fields of argumentation, and in the decades to come in political and professional debates, a new field was constructed by alternatively borrowing and differentiating from the fields of argumentation of both prenatal testing and population screening. How this process works can, for instance, be seen by looking at the role of the government. Fear of governmental pressure, as well as societal pressure appeared in discussions on prenatal genetic screening. The very fact that the government would organise and offer screening was perceived as exerting pressure. This line of thinking was further elaborated in the report ‘Genes and limits’ published by the Scientific Institute of the Christian-democratic party, CDA, in 1992. This political party was influential because during the 1980s and first half of the 1990s it had formed coalition governments chaired by prime ministers from the CDA. The report expressed the Christian-democratic viewpoint on modern genetic technologies and stated:

‘Population screening is aimed at potential prevention or treatment of disease ... in any case it may be perceived by citizens ... that the government by allowing population screening, would find it important ... to detect affected fetuses without prevention or treatment being available...’ (Scientific Institute of the CDA 1992). Also, preconceptional carrier screening was not found to be acceptable as it would burden the future parents with uncertain knowledge, and would eventually lead to a decision on whether or not to become pregnant and continue that pregnancy or terminate it.

For the time being, reproductive issues were deemed to be safely in the hands of obstetricians and clinical geneticists in the case of elevated risk, such as advanced maternal age. Prenatal diagnostic testing was offered to women of and over 36 years of age. For this group in the 1990s, serum screening gradually became an option. Though serum screening might be used as an additional or better risk assessment instrument than maternal age, ethical concerns were considered too significant. For pregnant women in general, serum screening was unavailable during the 1990s, thereby precluding parental autonomy to choose screening (Weinans et al. 2000).

New regulation

In 1996, the Population Screening Act (WBO: Wet op het Bevolkingsonderzoek), debated for many years, finally came into force. The purpose of the Act was to protect

people against potentially harmful screening. A special license was required to organise some forms of screening, such as population screening for disorders with no available treatment or prevention. For the latter, a licence would only be given in ‘exceptional circumstances.’ The Act underscored that treatability was a cornerstone of Dutch screening policy.

The Health Council of the Netherlands reflected on the new legal framework and the fact that prenatal screening would be subject to licensing in the absence of treatment or prevention. When discussing the legislator’s viewpoint that pregnancy termination constituted neither treatment nor prevention, the committee stated that abortion nevertheless could be seen as an appropriate course of action, under the circumstances (Health Council of the Netherlands 1994, 76). Clinical geneticist Leo ten Kate, one of the Council committee members, later noted:

‘The committee considered that “genetic screening should enable people to escape their fate by giving them the freedom to make an informed choice and adopt a chosen course of action which they regard as acceptable”... By taking this position, the committee freed itself from the restrictive viewpoint of the legislature and formulated a set of criteria to be met by genetic screening programs’ (Ten Kate 2000, 296). The Health Council report refined and elaborated earlier screening criteria, such as those by Wilson and Jungner (1968) and the Council of Europe (Committee of Ministers 1992). For our purpose, particularly the formulation of criteria 3 and 4 by the Health Council of the Netherlands (1994) are relevant:

3. The purpose of the programme must be to enable the participants to determine the presence or the risk of a disorder or carrier status, and to take a decision on the basis of that information.
4. Practical courses of action must be open to the participants.

By introducing a new focus on ‘courses of action’, a tension was created with the legal framework for population screening that insisted on ‘treatment’ as point of reference.

By explicitly restricting mass screenings to disorders for which a treatment was available, it was not clear what the consequences were for current practice of Down syndrome testing offered to pregnant women of and over 36 years. Since testing was perceived as individual health care, initially, it was expected to be exempt from licensing under the Population Screening Act. In 1996, however, it was agreed that testing based on maternal age should be considered as screening, since the test was not requested by an individual woman, but rather was offered to a specific group of women (Parliamentary Documentation 1995–1996). Because this kind of genetic testing by then had become standard practice, prenatal testing for Down syndrome for women of and over 36 years of age was granted a temporary licence.

A new century

After the turn of the century, developments in screening techniques, improvements in test characteristics, and a gradually rising interest in prenatal screening put the subject on the agenda again. For women of and over 36 years of age, it had become possible to have a serum screening test, women under 36 years of age could ask for one, which increased familiarity with prenatal screening. Having prenatal ultrasound screening ‘for fun’ became a new phenomenon that was discussed in women’s magazines. Around the year 2000, pilots were conducted with nuchal translucency and serum screening (van den Berg et al. 2005). New technological options and the implications for policy were discussed in the 2001 Health Council report ‘Prenatal Screening’ and its 2004 follow-up ‘Prenatal screening (2)’ (Health Council of the Netherlands 2001, 2004). In 2001, the Health Council reviewed several screening test methods. A triple test to be offered in the second trimester of pregnancy was considered as a suitable risk assessment screening for both Down syndrome and neural tube defects and should be aimed at all pregnant women, regardless of age. According to the Health Council, when certain conditions were met, such as an adequate procedure for informed consent, risk assessment for Down syndrome would be ‘such a superior alternative to the existing practice of maternal age-based screening that there should be no reason to delay its introduction any longer’. The Council argued that screening based on the triple test would lead to considerably fewer invasive tests and increased detection of Down syndrome pregnancies, while a far larger group would be allowed to benefit from having individual risk assessment. The introduction of screening for neural tube defects was considered a desirable step (Health Council of the Netherlands 2001, 28–29).

At the end of 2001, the Ministry of Health organised a Consultation round inviting several groups, such as obstetricians and patient representatives, to voice their opinions on serum screening (Toom and van Berkel 2003). In the same year, several obstetricians criticised the Health Council’s report in a medical journal. An important point of contention was that the birth prevalence of Down syndrome was higher in the maternal age group over 36 years of age. According to these obstetricians, by setting an age limit, potential psychological harm from screening younger women could be prevented (Hamerlynck and Knuist 2001). Another argument was that test characteristics for the group of older women were better than for the group of younger women. The number of false negatives in women under 36 years of age was found unacceptably high: approximately half of the cases of Down syndrome in pregnancies of younger women would not be detected, thereby giving false reassurance. In addition, the false

positives in the younger age group would require further testing. Based on figures from the Health Council, the obstetricians calculated that via invasive testing about the same number of cases of Down syndrome would be detected (115) as healthy foetuses would be lost because of test-induced iatrogenic abortions (111). Medicalisation of pregnancy was deemed undesirable (Kleiverda and Vervest 2001). The Health Council Committee had based its arguments on calculations for all age groups together. Representatives of the Committee responded by stating that compared to the current age-related diagnostic testing, the total number of invasive tests would drop. For the Committee, the option for women of all ages to consider a test was important (Van der Maas and Dondorp 2001) and was seen as a benefit, whereas the obstetricians stressed the burden of testing.

Offer screening only to 36+ women?

In November 2003, the State Secretary of Health sent a letter with the government’s reaction to the Health Council. In the statement, several arguments from previous years reappeared. The intention of the Population Screening Act to protect people against the potential drawbacks of screening was underscored. According to the State Secretary, the drawbacks of risk assessment screening for women under 36 years of age were considered greater than the benefits because their chance of having a foetus with Down syndrome was lower than for older women; medicalisation of childbirth for this group was to be avoided. Women over 36 years of age should be offered screening tests, as well as invasive diagnostic tests. If women under 36 years of age wanted a risk assessment test, they could ask and pay for it themselves. The State Secretary remarked that there were ample reasons to continue the restrained government policy regarding prenatal screening. She stated it confronts us with questions such as, whether medical framing of a natural process should be applied that ‘hardly’ raises problems for younger women, and that is seen by most of them as something positive; and whether this is a step towards a misleading ideal of a malleable humanity? (Parliamentary documentation 2003–2004a).

The danger of eugenics in population screening

In the arguments of the State Secretary and commentators, such as critical obstetricians, age limit surfaces as a watershed for population screening. In general, for population screening, benefit must outweigh harm (Wilson and Jungner 1968). The Health Council weighed the benefits of having the option to obtain risk assessment against potential harm for all pregnant women, whereas the State Secretary and critical obstetricians split pregnant women into subsets. When weighing pros and cons for younger women, it was

thought that the balance would be uneven while they would suffer from the psychological burden whereas their group risk was relatively small. However, the figures may relate to a more fundamental principle. Pregnancy is seen as a natural phenomenon and medicalisation of pregnancy in the form of prenatal testing places pregnancy in a category of potential danger. A moral argument is added: the question whether we consider life to be malleable and appropriate for tinkering. Here, we find an echo of the fears of eugenics. Whereas testing in individual high risk cases is more or less accepted, on a population level, prenatal screening can cause discomfort. The fact that the government would organise screening added to that sentiment (as discussed in the section above). People might think that particular screening would be acceptable and advisable in the interest of public health. The government could avoid using the instrument of population screening by maintaining the age limit and not offering serum screening to all pregnant women. Restricting screening to women 36 or older would fit into the existing paradigm of providing genetic services to persons with an elevated risk. What is relevant from a democratic point of view is that the government then makes the decision for younger women who cannot decide for themselves whether to have the screening test or not.

Freedom to take the screening test

In contrast to the discussion at the end of the 1980s, in the early 2000s, in Parliament and in the media, some critical questions were raised in response to the government's position. Especially problematic was the issue that women under 36 years of age had to ask for the test themselves, as the government was under no obligation to inform them of its availability nor was it possible to apply for reimbursement of the cost for the test. For women who lacked financial resources, had a lower education or a poor understanding of the Dutch language it would be difficult to have a test (Parliamentary documentation 2003–2004b). Also, a motion was brought forward urging the government to offer prenatal screening to all women (Parliamentary documentation 2003–2004c). In contrast to the reactions in the 1980s, when concerns were raised about whether women would have the option not to be tested, this time, in parts of society there were concerns about whether women would be able to have a test, if they wanted it.

In April 2004, the Health Council produced an updated report on prenatal screening (Health Council of the Netherlands 2004) and again suggested abandoning the age limit. They now suggested performing a combination test for Down syndrome in the first trimester—a blood test and a nuchal translucency measurement by ultrasound. For neural tube defects, an ultrasound test in the second trimester would be preferred.

The State Secretary of Health responded to this new advice and to the critical questions regarding her letter explaining the government's stand on the previous Health Council report on prenatal screening. She argued that based on new test developments giving information to all pregnant women on risk assessment tests by now was self-evident. However, women should have the option not to be informed if they did not want to. It should be made clear to women that they could reject screening, what the consequences of having a risk assessment test could be, and what further actions could take place in case of a positive outcome. Then, the woman could reflect on whether she would want to enter that trajectory at all. The restrained policy was continued, as was the age limit. It was argued that for women under 36 years of age, the risk of having a child with Down syndrome was lower, and the test would have more false positive and false negative outcomes than for the group who were 36 years of age or older. It was reiterated that it was not the aim to detect as many abnormalities as possible. Parents of children with Down syndrome or someone having Down syndrome should never be questioned as to why there had not been prenatal screening. For neural tube defects, the possibility of performing an ultrasound in the second trimester was studied further as recommended. The Health Council had suggested doing so, and representatives of obstetricians and midwives had urged to introduce this screening routinely, among others to strengthen the quality of standard care (Commissie Verloskunde 2003). Compared to the end of the 1980s, now there was support among health care professionals for prenatal screening for neural tube defects.

No treatment, no screening?

We would like to argue that these new policy developments in prenatal screening for Down syndrome and neural tube defects marked a shift from an emphasis on treatability and collective protection against harm by banning screening. Instead, offering options has moved to the fore as suggested in 1994 by the Health Council. Women are now given a choice, based on adequate information, to screen or not to screen for disorders in their foetus for which no treatment (in the sense of cure) is available. However, currently, prenatal screening for Down syndrome is not offered as part of an official population screening programme to women of all ages. The information on the screening is provided to all women, but women under 36 years of age have to pay for the screening themselves.

To complicate the picture, a second trimester screening, the standard anomaly scan (SEO: Structureel Echoscopisch Onderzoek), was introduced in 2007. It is offered to all pregnant women and reimbursed. Interestingly, this anomaly scan can detect both treatable conditions, such as certain

cardiac anomalies, as well as untreatable conditions, such as severe neural tube defects. The character of the technology has made maintaining the strict separation between the field of argumentation of population screening for health purposes on the one hand and the field of argumentation of genetic testing for untreatable disorders on the other hand problematic.³ By introducing this screening, in fact, a new standard integrating elements of both fields of argumentation is developing.

Although the standard anomaly scan does not resolve the conflicting aims of improving a foetus' health outcome versus gaining information about a possibly untreatable disorder as a basis for reproductive options, the woman or couple can decide whether or not to have the screening test. Much attention is paid to providing women with adequate information about risk assessment testing, as well as the option to decide not to be informed or not to have the screen. For Down syndrome screening, web-based decision aids have been developed (Raats et al. 2008; Meijer et al. 2010). This level of pretest information and counselling echoes the principle of informed choice in clinical genetics.

New trends

Since the 1980s, not only have techniques been developed that made it possible to screen an increasing number of pregnant women for a growing number of disorders, but public knowledge on and a demand for genetic testing has also increased. Another development has been the introduction of commercial testing. In the Netherlands, at the end of the 1990s, commercial companies started to offer so-called 'ultrasounds for fun', making it possible to have intrauterine pictures of the foetus. The fact that foetal anomalies were occasionally detected in the presence of parents who had not received any counselling was an extra impetus to regulate screening. Although a range of genetic tests is currently offered on the internet (Borry et al. 2010), until now prenatal testing has been predominantly offered via established centres of health care. However, the trend for commercialisation also implies that the 'old' governmental policy of not offering screening as a way to protect people against potential harm is becoming obsolete. If certain tests are not offered by the government, people may arrange to have testing in other, perhaps commercial, centres or hospitals in other countries, or via the internet.

³ Speaking of untreatable disorders in several cases is or has become questionable, and it would be better to regard these disorders as treatable 'to a lesser extent'. Recent advances in medication and care have made a significant contribution to boosting quality of life and life expectancy by tackling some aspects of the phenotype or co-morbidity.

Conclusion and discussion: Individual versus collective effects

In this new era, the individual woman or couple has gained more options to make an informed choice of whether or not to have reproductive screening. In principle, the availability of high-quality testing and the ability to make an informed choice might be welcomed as a positive aspect of present-day health care in modern democracies.

At the same time, it is relevant to note that individual choices add up to a collective effect: reproductive screening may become an increasingly 'normal' thing to do. Even if societal pressure is not explicit, implicit norms, comments and expectations from friends and family may frame the choices individuals can make. The sum of the individual choices may result in a 'collective eugenics' as visible in the number of screening tests being performed and in the reduction of the live births of foetuses with serious disorders that can be detected prenatally.

This mechanism, which is a cause for unease, can be demonstrated in other reproductive testing, such as Preimplantation Genetic Diagnosis (PGD) and will certainly surface again when new free foetal DNA testing is considered.

In the Netherlands, in 2008, PGD became the focal point of a public debate and almost caused the downfall of the Cabinet (Huijjer 2009). PGD had been applied rather unproblematically on a very small scale, for a handful of couples with a high risk of serious disorders in their offspring. When the government prepared new regulation of this practice, a public debate ensued in newspapers and on the television, among other things, over the question of whether disorders that are not fully penetrant, such as hereditary breast cancer, would also be eligible for PGD. Although patient groups, ethicists, and newspaper commentators, for instance, in the liberal newspaper NRC (NRC 2008), pleaded for this application pointing to the severity and high penetrance of the disorder, most notably representatives of Christian political parties and Christian patient groups called for a ban on this type of testing, arguing for the right to life and against eugenic tendencies (e.g. Kuiper 2008). Issues of (expected) scale figured anew as did the notion of the democratic right to make an informed choice (depicted as opposed to a 'religiously ordained' morale).

Whenever new technological options in prenatal testing become available, debate is called for to discuss the social and ethical ramifications. Especially, the tension between individual choice and the collective effects of creating a society without room for handicaps or illness, as a new form of collective eugenics, reappears. In the light of this tension, we would like to draw upon our Dutch historical case study to discuss the role of the government and public debate. Evidently, the role and responsibilities of the government have changed during the years. Instead of banning screening

that was found to be unsound and was perceived to have negative societal consequences, the government increasingly has taken up the responsibility to implement new forms of reliable reproductive testing and screening in an ethically sound manner, for instance, by providing adequate information and enabling informed choice, thereby changing the notion of protection. In addition, continuing efforts are necessary to boost the quality of testing and personnel performing the test. It is vital that policy should be in place to ensure standards of care for the handicapped, in order for people to have a real choice of whether to have testing or not, an issue that had already been raised in an earlier Health Council of the Netherlands (1989) report.

In modern democracies, public debate is essential for discussing values and practices implicated by governmental policy. It should be possible to voice a range of arguments for or against screening, and shed light on the mixed blessings and complexities involved (see also Huijjer (2009)). Until recently, both human geneticists and bioethicists have (rightfully) stressed the importance of taking the individual as a focal point when considering genetic testing. Given the recurrent argument of collective eugenics, public debate might be used to reflect on the ramifications of individual choice. Debate has just started on the host of ethical issues involved in whole genome sequencing, including sequencing of foetal DNA. Aside from the difficulty of analyzing and interpreting the data, issues include determining what information to report to parents and the right of the future child not to know its genetic makeup (Health Council of the Netherlands 2010; de Jong et al. 2010). Though this debate still seems confined to small groups of experts, the expected advent of free foetal DNA testing will soon open this debate to a wider audience. If or when such testing becomes a reality, the experiences with the standard anomaly scan might hold important lessons as to the difficulties in counselling and guiding parental reaction to information that may not always be conclusive about the nature of the suspected anomaly. In popular literature, accounts of how to deal with prenatal screening and foetal anomaly scan information, and how to live with the difficult decisions based on that information are appearing (Slagboom 2011). For societal actors, enriching public debate may entail discussing concepts and accounts of living with or without impairments and assimilating genetic information about oneself or one's offspring. These concepts change over time and instead of a 'collective eugenics', we might be able to discuss and produce new collective, yet varying images of 'the good life'.

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