

Prenatal diagnosis

The co-production of knowledge and values in medical research and public debate

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‘Your money or your life—A consideration of prenatal diagnosis’ ran the headline of an article published in several Swedish newspapers and magazines in the spring of 1978. It was written by three people with connections with the social care sector, and argued that prenatal diagnosis had profound social and moral consequences. It was now high time to have a wide-ranging debate about the values, justifications, and views underpinning its practice (Nordlund et al. 1978). The article was the prelude to an exhaustive public discussion about the direction, application and consequences of prenatal diagnosis. Developments in prenatal diagnosis had hitherto been a matter for the research community and the healthcare sector; now there was a demand for a broad public debate that could help shape national guidelines. This chapter shows how advanced medical technology such as prenatal diagnosis was discussed, evaluated, and renegotiated when translated from laboratories and clinics into the public arena and the debate about policy and regulation.¹

The chapter draws on the theory of co-production, which describes how the development of scientific knowledge and its applications takes place in constant interactions with society’s norms, values, and interests (Jasanoff 2004). Neither the production of knowledge nor its applications can be understood without

considering the social and political contexts that are its preconditions. In this chapter, it is the movement of knowledge from research and clinical context out into public debate that is the main concern, and above all the question of policy. The focus is the notion of prenatal diagnostic practice represented by medical experts (medical researchers and doctors) and the views on prenatal diagnosis expressed in the media and in policy proposals. I analyse how notions of medical technology's practices and consequences were debated and questioned when medical knowledge moved from the laboratory and the clinic to the public sphere. When groups outside the research community debated prenatal diagnosis, other interpretive frameworks, contexts, and values were introduced, compared to those which had been central when the technology developed in the laboratories and the clinical context. The analysis shows there were different views about prenatal diagnosis in the public debate and the policy context, which differed somewhat from the medical experts' views. One conclusion of the present study is that the application and regulation of complex medical technologies require a continuous, unflinching public discussion in which both experts and representatives of different sections of civil society participate (Jasanoff 2005). Such discussions are the prerequisite for democratic decisions about biotechnologies which have the potential to influence people's fundamental ideas about *life itself* (Rose 2007), while at the same time retaining the scientific legitimacy of medicine.

The chapter covers a brief historical background and the broad outlines of the medical developments in prenatal diagnosis, before turning to the public debate and the official inquiry into prenatal diagnosis by the Swedish National Board of Health and Welfare in the early 1980s as part of the formulation of a national policy. First, the concept of co-production, and how it can be employed to understand what happens when knowledge moves between contexts, is discussed. The source material consists of articles in newspapers and magazines, particularly for the public debate, and the official inquiry proceedings, including the written responses by relevant

organizations and government agencies; this material provides a broad cross-section of the opinions on prenatal diagnosis found in Swedish society in the late 1970s and early 1980s. Several opinions had historical resonances, expressing historically-shaped notions of health and disease, deviation and normality. The historical perspective can therefore help conceptualize how medical knowledge has evolved, stabilized and changed, not only in its translation from one context to the next, but also between different periods.

The embeddedness of knowledge

There is a well-established notion in the history of science and science and technology studies that knowledge is embedded—that its content cannot be separated from the social, political, and cultural contexts in which it is produced and applied. The context plays a role, both for the knowledge produced and for how that knowledge is perceived, applied, and used. One expression of this is Sheila Jasanoff's concept of co-production:

the ways in which we know and represent the world (both nature and society) are inseparable from the ways in which we choose to live in it. Knowledge and its material embodiments are at once products of social work and constitutive of forms of social life; society cannot function without knowledge any more than knowledge can exist without appropriate social support. Scientific knowledge, in particular, is not a transcendent mirror of reality. It both embeds and is embedded in social practices, identities, norms, conventions, discourses, instruments and institutions—in short, in all building blocks of what we term the *social*. (Jasanoff 2004, 2–3)

Our knowledge and our ideas about the world cannot be disconnected from the society in which we live. Biomedical knowledge produced in a laboratory or any other research environment is equally part of its social, meaning-making context. This means

that when this knowledge is translated from knowledge-producing to applied knowledge contexts, it will both influence and be influenced by the latter context. Co-production is therefore a useful perspective for understanding how social, political, and cultural values interact with knowledge in the phases of its construction, mobilization, and application, wherever in society it is (see Lindh in this volume).

According to Jasanoff, some situations lend themselves to making the embedded nature of knowledge visible. One is when new technologies are established, questioned, stabilized, and eventually regulated in a society. Prenatal diagnosis was just such a technology. It was developed in a scientific and medical context moulded by certain views and values; when it became the subject of public debate, it came up against differing views and values. This was particularly true of views on people with disabilities, but also opinions on what constitutes human life, reproductive rights, and the direction of future medical research. The debate about prenatal diagnosis thus not only shows how new technology is discussed and questioned when it moves out of the laboratory or clinic, it also shows that when a new, complex technology is introduced, a variety of social, political, and ethical views are mobilized, which will be discussed in this chapter.

The historical roots of prenatal diagnosis

Prenatal diagnosis developed from knowledge in such disciplines as medical genetics, clinical chemistry, and obstetrics, of which the advances in medical genetics played a significant role, as the diagnosis of genetic diseases was a major part of the first prenatal diagnoses. One particularly important discovery was made in 1956, when the geneticists Albert Levan and Joe Hin Tjio found that humans have 46 chromosomes, not 48 as thought (Harper 2006). Three years later, the French paediatrician and geneticist Jérôme Lejeune and his co-workers suggested that Down's syndrome was caused by an extra chromosome. The same year, 1959, it was found

that Turner's syndrome and Klinefelter's syndrome are both sex chromosome disorders, and the following year further links were found between chromosomal abnormalities and specific syndromes (Kevles 1995; Lindee 2005; Löwy 2017).

At first this new genetic knowledge was used to diagnose patients or confirm diagnoses, and soon it came into use in genetic counselling, which became established at a handful of hospitals in Sweden (Björkman & Tunlid 2017). The background of genetic counselling can be found not only in the emerging field of medical genetics, but also in the eugenics movement of the early twentieth century, with the latter's aim of controlling the genetic composition of the population (Broberg & Tydén 2005).² An important element in Swedish eugenics was the 1934 and 1941 Sterilization Acts, which allowed for sterilization of individuals classified as legally incompetent without their consent.³ A group that was specifically targeted was the 'feeble-minded', who were judged to be genetically inferior and a social and economic burden on society, and whose procreation was assumed to weaken the population's genetic composition (Tydén 2002). Eugenics, however, was a multifaceted movement that was not only government-driven; the spread of eugenic ideas in Swedish society meant that individuals learnt of the significance of their genetic inheritance, and turned to genetic experts for advice on reproductive health (Björkman 2015). Often they were afraid they might have children with disabilities or serious diseases.

In developing medical genetics and genetic counselling in the post-war period, many geneticists emphasized the individual's right to make their own decisions and asserted that counselling was not intended to improve the heredity of the population. Most historians agree, however, that eugenic ideas and practices did not end with the Second World War (Bashford 2010). Exactly which parts of the eugenic mindset were abandoned and which were transformed and lived on into our own time with its ever more advanced genetic and reproductive technologies is much debated. As the historian of biology Nathaniel Comfort (2012) suggests, perhaps 'the eugenic impulse'—the urge to eliminate disease, improve health, and reduce

suffering by controlling human heredity—has been one of the most enduring in this history. It certainly comes with a variety of sociocultural values about what constitutes good health, well-being, and quality of life, married with the wish to choose certain traits and reject abnormalities and diseases when making reproductive decisions. As will be seen, it was around these choices that much of the debate about prenatal diagnosis revolved.

From statistical risks to information about the foetus

Before the advent of prenatal diagnosis in the 1970s, the methods available to geneticists for genetic counselling were based on statistical analyses of the risk that parents would pass on a certain disease or disability to their children. These estimates were based on known inheritance mechanisms and experience-based knowledge of how diseases were inherited. Armed with this knowledge and a map of the family's disease patterns, the geneticist calculated the risk of a hereditary disease being passed to any future children. Those who received genetic counselling were thus told there was a risk, expressed as a percentage, of passing a specific disease or disability to their children. This figure for risk was what parents had to consider when contemplating pregnancy.

The point of genetic counselling, according to the Swedish paediatrician and medical geneticist Karl-Henrik Gustavson, was 'to provide factual information about the hereditary or non-hereditary nature of the disease and to communicate how great the risk will be for subsequent children' (Gustavson 1967). According to Gustavson, genetic counselling had no eugenic purpose, and existed only to help individuals or families with their 'special problems'. The notion that patient autonomy would be respected was often emphasized to underline it was the interests of the woman and the family which were paramount, not the state. The genetic counsellor's job was to provide the woman with objective, neutral information, and not to influence her position on a new pregnancy. However, Gustavson and other genetic counsellors knew the risk figures on which they

based their advice could be difficult for laypeople to grasp, as there were such variations in people's notions of significant and minor risk or the severity of a disease or birth defect. Moreover, parents often felt guilt and shame about the risk of passing on hereditary diseases or disabilities to their children (Gustavson 1967; Lindsten et al. 1975). In practice, genetic counselling was a very complex business, open to interpretation and value judgements. Risk calculations could be presented in different ways, as could information about the diseases or disabilities concerned. Medical knowledge thus came to be embedded in certain notions of disease, abnormality, and normality that were largely characterized by medical expertise.

The circumstances in which women made reproductive decisions changed dramatically in the early 1970s with prenatal diagnosis, made possible by medical genetics and the invention or improvement of several medical technologies. One of these was amniocentesis, a procedure in which a small amount of the amniotic fluid is removed from the amniotic sac. In the late 1950s it was found that the cells in the amniotic fluid could be used for foetal sex determination—knowledge that was central to the diagnosis of sex-linked hereditary diseases. However, it was only in the late 1960s that cells were first cultured from the amniotic fluid, which was crucial for analysing chromosomes. Another important technology in this context was medical ultrasound, which in the early 1970s improved the ability to withdraw amniotic fluid (Löwy 2017).

If a woman underwent prenatal diagnosis, the information she was given no longer concerned the risk of a particular disease, but the specific condition of the foetus she was carrying. Amniocentesis made it possible to detect chromosomal abnormalities and determine the foetal sex. Doctors were also able to diagnose a number of unusual but serious metabolic disorders and to establish if there was a risk of spina bifida, a neural tube defect. Instead of multiple or complex risk figures, a woman who underwent prenatal diagnosis and found that the foetus had a disease or condition could decide whether to terminate the pregnancy.

The development of prenatal diagnosis occurred in parallel with

calls for more liberal abortion laws in Sweden (Lennerhed 2017). Under the 1938 Abortion Act, there was the possibility of legal abortion, but only in certain circumstances: the woman had to apply for an abortion, and it could be granted only with reference to certain specific indications.⁴ One was the ‘eugenic indication’, which meant the risk that a parent would transmit ‘insanity, mental retardation, or severe physical disease’. In 1963, in the wake of the thalidomide tragedy, foetal defects were added as an indication. Although the number of abortions on eugenic grounds declined in the post-war period (Tydén 2002), abortion due to a suspected hereditary disease or condition was a well-established practice in the Swedish health service.

In 1974, a new Abortion Act was passed that gave the woman the right to elect to have an abortion up to 18 weeks of pregnancy, after which an abortion was only permitted in exceptional circumstances with the permission of the National Board of Health and Welfare.⁵ Permission could be given until the foetus was considered viable, which in practice meant the end of 22 weeks. The majority of applications for abortion due to a birth defect were granted by the National Board of Health and Welfare, since the test results of the prenatal diagnosis were usually not available until after 18 weeks of pregnancy. Abortions due to diagnosed foetal defects were called selective abortions, distinguishing them from the general abortions when the pregnancy was unwanted.

The introduction of prenatal diagnosis

Prenatal diagnosis was introduced in the Swedish health service in the early 1970s. It was primarily offered to pregnant women over a certain age (it had long been known that the risk of Down’s syndrome increased with maternal age) and women with disability or genetic disease in the family. A third group was women who, for other reasons, had strong concerns about having a child with a disability or genetic disease.

Prenatal diagnosis was thus targeted at individuals and families

in specific situations. It was seen by doctors as helping women in the designated risk groups by detecting several serious hereditary diseases and disabilities early in pregnancy, and meant that a foetus with one of those diseases or a chromosome abnormality could be aborted if the woman so wished, while an abortion could be avoided if the foetus was healthy. Families who ran a high risk of having a child with a disability or genetic disease could thus be 'guaranteed that any future child would not have the hereditary disease for which they had an increased risk' according to some of the leading doctors in the field (Kjessler et al. 1972, 2362): their view was that prenatal diagnosis led to greater numbers of healthy children being born, and a reduction in the number of abortions of healthy foetuses. The new technology was thus described by the doctors as improving women's opportunities to make informed reproductive choices. However, it could also be described as the prospect of greatly reducing 'the number of hereditarily defective children' (*Svenska Dagbladet* 17 Mar. 1971). In a letter to the National Board of Health, three doctors argued that prenatal diagnosis should be extended as follows:

Through prenatal diagnosis, parents can be reassured early in pregnancy with accurate information. If the expected child is healthy, one can thus avoid the abortion of a healthy foetus. If the diagnosis of the child is positive, and if the mother wishes to terminate the pregnancy, society can be expected to save significant sums, which would otherwise be needed for the future institutional care of the defective child. If only a small proportion of the money so saved is made available for prenatal diagnosis, something of benefit to both individual and society could be achieved satisfactorily.⁶

The reproductive choices of women and families were expected to fall into line with society's interest in cutting the costs of healthcare and social care for disabled and seriously ill children. The expense of expanding prenatal diagnosis and genetic counselling could

therefore be justified on socio-economic grounds, compared with the costs of health and social care (Lindsten et al. 1976).

The possibility of using prenatal diagnosis to prevent the birth of children with disabilities was noted in several contexts. In Sweden's medical journal, *Läkartidningen*, two paediatricians, Bengt Hagberg and Karl-Henrik Gustavson, expressed the hope that prenatal diagnosis would progress to the point where a simple blood test early in pregnancy would detect if the foetus had Down's syndrome. It was their belief that 'a preventive approach' to mental disability was justified not only on humanitarian grounds but also on financial ones. According to their calculations, the cost to the taxpayer of a single 'severely mentally disturbed child' in institutional care was SEK 1.2 million a decade (Hagberg & Gustavson 1978). It is unclear what they meant by humanitarian grounds, but it may have been both the family's situation and the child's, as doctors often said that disabilities and hereditary diseases caused suffering to both children and families.

The early discourse of prenatal diagnosis, in which doctors and medical experts took the lead, therefore had several elements. It was based on medical advances which gave women greater opportunities to make reproductive choices, but it also plainly involved value judgements about serious diseases and disabilities. The individual's right to choose in the question of abortion was combined with a belief that there was a public interest in reducing the number of people with genetic diseases or disabilities. The discourse also spanned such notions as disease, suffering, and normality. Children with genetic diseases and disabilities were often described as defective, and their condition a source of suffering for them and their families. Prenatal diagnosis, combined with abortion, was seen as a way of preventing this suffering. In this way the new technology was placed in a context characterized by certain norms and values.

When medical notions of foetal diagnosis were debated more generally, it was primarily in terms of two contemporary discourses: one that stressed women's rights to make independent, well-informed choices about reproductive issues, and one about

perceptions of people with disabilities and their place in society. Alongside this was a discourse about the right to abortion per se, but it hardly featured in the debate under consideration here. There was no organized anti-abortion movement in Sweden at this time, although there was a belief, especially in Christian contexts, that abortion rights should be restricted.⁷

Public interest in prenatal diagnosis

At first, the debate about prenatal diagnosis was limited to the medical context, with a few exceptions (see Gustafson 1980). An early attempt to address the wider implications of the technology was mounted by the Liberal politician Kerstin Anér in a high-profile motion in Parliament in 1972 on the inviolability of the individual, in which she stressed that society faced a difficult, complex situation because of recent medical and technological advances. One was prenatal diagnosis, which according to Anér could soon lead to the question of whether it was a right for all pregnant women to be informed of any genetic diseases, and whether that right would bring with it a duty to abort any foetus with a defect. Anér asked whether ‘society would be the child’s advocate and say you have the right to live; or you have the right not to live’. The motion resulted in a proposal to set up a working group to discuss the social and legal consequences of medical developments, and whether there were grounds to impose any restrictions on medical research (Anér 1972). After an extensive consultation process, the parliamentary motion was rejected.⁸

There had been little public discussion, though, by the time ‘Your money or your life’ was published in the spring of 1978. The debate which the article sparked, and the demand for practice guidelines for prenatal diagnosis from the medical authorities, led the National Board of Health and Welfare to appoint an official inquiry in 1980. It brought together doctors and other medical experts to clarify and describe the central issues of prenatal diagnosis. As the Director General of the National Board of Health and

Welfare said, the advances in medical research had determined the direction taken, and now it was important to clarify whether society should influence future developments (Socialstyrelsen 1982). The inquiry's interim report addressed both the medical and technical aspects of prenatal diagnosis and the psychological, ethical, and legal ramifications. It also asked several questions about the application of prenatal diagnosis. The interim report was circulated for public consultation to various public authorities and organizations as normal, resulting in the submission of a very large number of official consultation responses.

The public debate, like the consultation responses, addressed a range of broader issues and problematics. In what follows, three central themes in this material have been singled out. First, the importance of prenatal diagnosis for views on people with disabilities and the socio-economics. Second, foetal rights and the situations in which it was right to terminate a pregnancy—a theme that tied in with the public debate about abortion per se, and also the question of prenatal diagnosis and selective abortion. Third, the implementation and regulation of prenatal diagnosis, including whether there were reasons to change the standing abortion legislation, a theme with a bearing on reproductive rights as formulated in the 1974 Abortion Act. Also considered here is the side theme of the nature of medical research, and whether there was reason to redirect or limit the research relating to prenatal diagnosis.

Prenatal diagnosis and disability

The article 'Your Money or Your Life' dealt pointedly with the three points that the authors said had been the key arguments for prenatal diagnosis: reducing the suffering of families with children with disabilities, reducing the suffering of the child, and reducing the cost to society. To the first argument, the authors said that the remedies were social measures and changed attitudes. The idea that prenatal diagnosis could reduce the suffering of people with disabilities was also called into question, because only those with

a disability or their immediate relatives could decide what constituted a meaningful life. However, according to the authors, the humanitarian arguments were overshadowed by the third argument concerning economics, and they cautioned that in a society driven by profitability, efficiency, and the rational use of resources, people with disabilities were dismissed as unprofitable. According to them, this was the chief reason for offering prenatal diagnosis (Nordlund et al. 1978).

The claim that the impetus behind prenatal diagnosis was socio-economic outraged several doctors, who countered that the primary reason was to reduce the suffering of children with severe congenital diseases, disabilities, or birth defects, and the same went for families too. It should be noted here that suffering would be alleviated by the abortion of foetuses with those diagnoses—there was no possibility of treatment in utero. Furthermore, according to the doctors, the possibility of prenatal diagnosis would allay the fears of parents worried about future pregnancies. The socio-economic arguments were now toned down and the medical and humanitarian aims emphasized (Gustavson 1978; Kjessler 1979). However, even among doctors there were those who wondered whether Down's syndrome could justify abortion on the basis of diminished suffering. Stig Melander, a senior consultant at the department of obstetrics and gynaecology in Norrköping, wrote that 'It is a widely accepted fact that the mongoloid as a conscious, living person does not suffer to any appreciable extent from his condition' (Melander 1978). Despite this, an increasing number of pregnancies were terminated due to Down's syndrome, and it could not be ruled out that this affected people with disabilities:

The hardest thing for many people, as for me, however, is the idea of those disabled individuals who have already been born, who are aware of their situation. How can the disabled view this state of affairs, this reasoning, as anything other than deeply humiliating and offensive? If I were on the way now, would you others have made sure I never came into the world? I am a deeply unwelcome

citizen. Can anyone help convince me that I don't look at them this way? (Melander 1978)

The Swedish disability movement was divided in their view of prenatal diagnosis. The reasons for and against were many, and related to attitudes towards people with disabilities and the support for them and their families. Many parents of children with disabilities found there were major deficiencies in social support, and the pressure on them to take care of their disabled children themselves was at times described as 'an unreasonable workload' (*Dagens Nyheter* 10 June 1980). From this perspective, the possibility of prenatal diagnosis could be felt important for future pregnancies. Yet there was a strong concern within the movement that prenatal diagnosis would end in quality checks on all fetuses, with people with disabilities thought an undesirable group in society. Another concern was that the voluntary nature of testing and abortion would be eroded: prenatal diagnosis might seem obligatory rather than an option, and abortion the self-evident choice if a disease or disability were diagnosed.

At first, however, the disability movement was cautiously positive about prenatal diagnosis. In the early 1970s, the Swedish National Association for People with Intellectual Disability (FUB), which largely organized parents who had children with disabilities, argued that genetic counselling should be expanded, because many of its members were worried about having another child with the same diagnosis. Over the 1970s, though, fears grew that prenatal diagnosis would lead to selection and eventually the emergence of an elite society. In essence, the disability movement tried to defend the rights of people with disabilities while supporting access to prenatal diagnosis for individual families. Prenatal diagnosis could be justified on an individual basis, whenever the expectant parents felt themselves incapable of caring for a child with a disability. 'We couldn't cope having another mongoloid child,' as one parent put it (Wahlström 1974). The debate within the FUB became more heated in the late 1970s when the question of human dignity and societal issues was raised. Prenatal diagnosis was said to be 'not

primarily a question for experts—but about views on human dignity and what kind of society we really want' (*FUB-kontakt* 1978). FUB representatives rejected the standard argument that prenatal diagnosis could prevent suffering. For example, it was indefensible to say that all children with Down's syndrome suffered, and it was virtually impossible to know in advance what life would be like for them (*Stockholms-Tidningen* 22 Nov. 1982).

In its official consultation response to the National Board of Health and Welfare's report, the FUB stated that it represented an uncompromising view of humankind: 'Each person has a unique value in themselves. Even a severely disabled person has an infinite value, and the right to our respect and love.'⁹ Any tendency to question the right to be born or to live with full human rights, regardless of disability, had to be fought, and efforts had to continue to direct research and find resources to provide life chances for children with disabilities and their families. However, the possibility of prenatal diagnosis could not be rejected. According to the FUB, Sweden's abortion legislation and the rules on free abortion were incompatible with the prohibition on abortion on the basis of birth defects; it stressed, however, that its position had nothing to do with the attributes of the foetus, but on the family's situation, and whether the woman judged that the family had the resources for a child who required extra care.

Likewise, the Swedish Disability Federation Central Committee (HCK), an umbrella body for several disability organizations, was initially in favour of prenatal diagnosis, arguing it could prevent disability (Gustafson 1980, 66). However, by the time of its official consultation response to the National Board of Health and Welfare's report, the HCK, much like the FUB, emphasized the equal right to dignity and that society had to provide support so everyone would have equal treatment.¹⁰ The HCK could not accept prenatal diagnosis 'designed to sift out the people who will not be allowed to live'. Nor should the severity of the birth defect determine whether an abortion was defensible. For the HCK, the ethical issue was not one of degree; the conflict existed in the idea that one could 'quality

assess' a foetus. Rather, it emphasized the importance of changing society so the consequences of disabilities could be compensated for or prevented. Many of the HCK's members were worried that tolerance of people with disabilities would wane and that society's resources for the group would stagnate or be cut. That said, it did not reject prenatal diagnosis out of hand. What it objected to was prenatal diagnosis predicated on the abortion of all foetuses with a defect. However, it could support 'foetal-focused therapy', or prenatal diagnosis focused on the treatment of foetuses.

Segments of the disability movement clearly distanced themselves from prenatal diagnosis, however. For example, the Swedish Association of the Visually Impaired 'forcefully' rejected

all prenatal diagnosis designed to cull human populations. No disability could possibly justify abortion in a democratic society. Any other approach can have devastating effects on how people with disabilities are viewed. But it can also lead to the foundations of democracy and views on people and people's worth are changing beyond recognition.¹¹

There may have been several reasons for the disability movement's varied views on prenatal diagnosis. One was that the associations of parents of children with disabilities were often more cautiously positive than those associations of people with disabilities (Gustafson 1984). Being the parent of a disabled person often carried great responsibility. Attitudes may also have been affected by the severity of the disability. Although several associations objected to rating various disabilities and conditions, that did not rule out that parents who already had children with very severe disabilities and significant care needs were in favour of prenatal diagnosis.

The socio-economic arguments, though, were firmly and unanimously rejected by the disability movement. In the early 1980s that case was still being made, with talk of cost-benefit analyses and calculations of the economic gains to be had from the increased diagnosis of birth defects and subsequent abortions and saved care

costs. 'However you want to count it, prenatal diagnosis is very profitable for society', as a county council politician put it (Åkerman 1982; *FUB-kontakt* 1982). Disgust at this sort of calculation went far beyond the disability movement: it opened for 'general hatred of disabilities', wrote the Social Democratic newspaper *Stockholms-Tidningen* (5 July 1982), which thought the question ought to be discussed in terms of society's general support for people with disabilities. Only societies which included them could avoid prenatal diagnosis becoming an instrument for selecting and removing 'non-perfect' people.

Foetal rights

Another theme in the debate about prenatal diagnosis was the rights of the foetus and the ability to diagnose and possibly treat foetuses with birth defects. As the conservative newspaper *Svenska Dagbladet* (9 Dec. 1979) said, this could reasonably be expected to raise the ethical question of whether the foetus is a person with the right to life and not part of the woman's body. The Swedish Medical Society reasoned along similar lines in its views on the ethics of prenatal diagnosis, stating that the possibility not only of diagnosing but also treating foetuses would probably lead to the rights of the foetus as an independent individual being respected to a greater extent 'than is now the case' (Svenska Läkaresällskapets delegation för medicinsk etik 1980). Before the new Abortion Act was passed in 1974, the Medical Society's Delegation for Medical Ethics had stated that the foetus had its own life, and that as a potential human should be given legal protection; however, it was omitted from the new legislation (Svenska Läkaresällskapets delegation för medicinsk etik 1979). Thus, it was a view that enjoyed a resurgence because of the ability to diagnose and possibly treat in utero. The debate about prenatal diagnosis therefore evolved to include the question of when the human embryo could be regarded as having personhood.

This and many other issues were covered by a special inquiry on the medical ethical aspects of prenatal diagnosis appointed by

the Swedish national synod in 1979.¹² Medical experts as well as theologians sat on the inquiry panel.¹³ As described in their report, prenatal diagnosis had three aims: to prevent the abortion of healthy fetuses; to develop methods for treating fetuses before any permanent damage; and to provide a basis for a decision to possibly terminate a pregnancy. These were the three aims doctors had always recognized. The synod inquiry was unanimous that the first two aims could be accepted without reservation, so it concentrated on the third—abortions after prenatal diagnosis. Opinion was divided on these so-called selective abortions, but the synod inquiry could agree that they were part of ‘the much larger and ultimately fundamental problem of abortion’ (Fagerberg 1980, 8). It amounted to the foetus’s right to life. Prenatal diagnosis was thus tied to the questions of the point at which the fertilized egg or embryo had personhood and at what point it merited protection. This went hand in hand with an ongoing debate about euthanasia—the circumstances in which it was right to actively end a life—and the 1974 Abortion Act, which, according to the synod inquiry, had not addressed the rights of the foetus. The synod inquiry’s various positions on these questions were summarized by the chairman of the Swedish Medical Society’s Delegation for Medical Ethics, who hoped that a ‘more thorough and nuanced discussion of abortion than the one which preceded the 1974 decision would now be possible’ (Giertz 1980, 117).

However, according to the synod inquiry, selective abortions were, to some extent, special compared to general abortions. The pregnancy was initially desired, but the foetus was found to have a disease or defect. Further, they were often performed late in pregnancy. ‘In these circumstances, no one can ignore the fact that life is extinguished because it is not desirable,’ said Gustav Giertz, physician and chairman of the Swedish Medical Society’s Delegation for Medical Ethics (Giertz 1980, 119). The synod inquiry could not agree on whether such abortions should be considered ethically defensible or not. Views ranged from certainty that the Abortion Act accurately reflected current norms to calls to safeguard the rights of the foetus and a belief that abortion was only ethically acceptable

under special conditions such as incurable and fatal birth defects or danger to the mother's physical or mental health. The synod inquiry did not believe the Abortion Act should be changed, but did not preclude a situation when diseases of the foetus could not only be diagnosed but also treated, meaning that the legal status of the foetus as an independent individual would have to command far greater respect. According to Archbishop Olof Sundby, advances in prenatal diagnosis had reinforced an awareness of the respect for the life of the foetus (*Upsala Nya Tidning* 17 June 1980). The inquiry attracted considerable attention, placed the foetal rights on the agenda, and by extension fuelled the wider debate about prenatal diagnosis and abortion (*Dagens Nyheter* 17 June 1980; *Svenska Dagbladet* 18 June 1980). The medical knowledge generated by prenatal diagnosis as it moved to other contexts than its original genetic, medical context thus prompted new questions—or brought to life old ones—of which several concerned conflicting norms and values.

Practice and regulation

When prenatal diagnosis was introduced in the Swedish health service, it was with no specific guidelines or regulations. Much of the public debate had turned on the question of how prenatal diagnosis would be implemented, what would be allowed, and whether specific regulations were required besides the 1974 Abortion Act. Many of the voices in the debate were worried about what the future held. The liberal newspaper *Dagens Nyheter* wondered whether prenatal diagnosis could become mandatory, and what choices parents would be faced with: 'Will the authorities permit diagnosed harmful genes to be reproduced? Will the taxpayer, who will foot the bill, tolerate that foetuses suspected to be defective become people?' (*Dagens Nyheter* 18 June 1980). The eugenicist mindset was cited as a warning lesson. The disability movement also demanded regulation. According to the HCK's registrar, Rolf Utberg, not every disease was grounds for abortion. As he wrote, 'I believe that all kinds of people should be welcome and that we

should have very strict rules for how prenatal diagnosis should be conducted' (*Dagens Nyheter* 27 July 1982).

The question of guidelines or regulations was also raised by the National Board of Health and Welfare in its inquiry into prenatal diagnosis. Who should be offered prenatal diagnosis? Was there cause to change the 1974 Abortion Act? Should a woman have the right to choose, even if the reason for an abortion was the foetus's attributes? On the first question, many consultation bodies—except those which flatly rejected prenatal diagnosis—accepted the practice developed by the Swedish health service of prenatal diagnosis being offered to special risk groups. However, segments of the disability movement were critical of the concept of 'risk groups', which often featured in the debate, and argued vigilance was needed so attitudes towards people with disabilities would not gradually worsen.¹⁴ In medical quarters, meanwhile, the view was that fear and anxiety felt by women was as important a reason for prenatal diagnosis, and that any rules had to be adaptable to the individual situation.¹⁵ It is interesting to note that in its consultation response to the National Board of Health and Welfare's report, the Swedish Medical Association argued that the final rules for prenatal diagnosis and the resources it would attract should be the subject of a broad parliamentary inquiry, as 'the correct democratic approach.'¹⁶ This was not detailed in the consultation response opinion, but was in line with views expressed by individual doctors (*Dagens Nyheter* 23 July 1982), perhaps an indication of the need for clinical praxis consistent with society's values and norms.

Thus while the majority of consultation bodies believed that prenatal diagnosis should be available to certain groups, many were critical of screening, with all pregnant women offered the tests to detect serious birth defects.¹⁷ Several consultation bodies stressed that prenatal diagnosis had to be voluntary, and if it came to screening it could impose such pressure on women that in practice it would be difficult to say no. Even voluntary testing made some uneasy, not least in the disability movement, for whom just the offer of prenatal diagnosis was problematic, concerned that in practice women did not

have freedom of choice. It could be difficult to refuse. 'The entirety of the technological situation with its (ostensible) accuracy and effectiveness exerts a strong manipulative influence. There is little scope for questioning, reflection, and emotional evaluation. It is simplest and best to let technology have its way', wrote the Swedish Heart and Lung Association.¹⁸ According to the National Association of the Disabled, if a foetus was found to have defects abortion was not voluntary, as there was a very strong pressure on the woman in this situation to abort, something that the National Board of Health and Welfare (*Socialstyrelsen* 1982, 81) also noted in its report.¹⁹

The question of altering the right to free abortion was closely linked to rapid medical developments, which meant that an increasing number of foetal diseases and abnormalities could be diagnosed ever earlier. According to the inquiry, there was an evident risk of 'quality checks' on the foetus and a greater number of abortions for less serious abnormalities. The measures considered included the possibility of increased surveillance of abortions due to birth defects, and partial restrictions on the right to have an abortion due to birth defects. Regarding surveillance of abortions due to birth defects, the inquiry asked whether a woman who wanted to have an abortion between weeks 14 and 18 of pregnancy should have to state her reason. Since the results of prenatal diagnosis were rarely available before the end of week 18, the majority of abortions due to birth defects were decided by the National Board of Health and Welfare (though in principle it always gave permission); they therefore had a good overview of the reasons given. If more birth defects were diagnosed before week 18, the inquiry feared this supervisory aspect would be lost 'unless special steps were taken'. At least initially, the proposal that a reason would have to be given for an abortion between weeks 14 and 18 was not designed to limit a woman's right to an abortion. However, future changes were not ruled out (*Socialstyrelsen* 1982, 106).

By extension, the inquiry foresaw 'bigger problems' arising from future medical developments, namely that minor abnormalities would increasingly be detectable. Would this justify imposing limits,

deciding which birth defects would be considered valid grounds for an abortion? The inquiry emphasized that regulation would scarcely be possible without overruling women's autonomy, and it therefore asked whether abortion on the grounds of birth defects was such a problem it justified tearing up the basic principle of the abortion legislation, namely a woman's right to choose. Was it the woman's right alone to decide to have an abortion, even when the reason was the foetus's traits?

To check the reasons for abortions between weeks 14 and 18 or to restrict the woman's right to choose would require changes to free access to abortion. Most consultation bodies strongly opposed any such restrictions, and especially the majority of the women's movement, the campaign for the 1974 Abortion Act fresh in their minds. This did not prevent many women's organizations commenting on the National Board of Health and Welfare's report that it was an ethically complex issue, which would affect society's views on disability.²⁰ Social Democratic Women in Sweden was one organization to emphasize that for decades women had fought for the right to abortion, including the right to decide without giving a reason. They did not agree that the fundamentals of the 1974 Abortion Act had changed.

Then as now, we hold that in balancing the foetus's right to development on the one hand and its right to be born into human dignity, the latter must weigh more heavily. *Then as now*, we contend it is the mother alone who can determine whether the conditions of human dignity can be met.²¹

Even the Fredrika Bremer Association, one of the oldest Swedish women's organizations, stressed the importance of free abortion: 'Now, as before, we wish to state our belief that a woman's right to decide about the possible termination of a pregnancy may not be limited.' For them it was 'obvious that the woman bases her judgement about a possible termination of a pregnancy on whether she can, whether she dares, assume responsibility for the child ... Who better

than the woman to judge what she can cope with.²² The Women's Political Committee of the Left Party Communists also stressed women's ability 'if supported to take difficult decisions,' and there was no reason whatsoever to restrict the 1974 Abortion Act in the light of advances in prenatal diagnosis. It could not be construed any other way 'than as a distrust of a woman's ability to decide for herself on what conditions she wants to give birth.'²³ The women's political association that most disapproved of prenatal diagnosis was, not surprisingly, the Christian Democratic Women's Association, their view being coloured by their general dislike of the 1974 Abortion Act. Their precept was the sanctity of life and the equal dignity of all, and they believed abortion was a last resort.²⁴

One of the most determined defenders of a woman's right to choose was the Swedish Association for Sexuality Education (RFSU), a non-profit organization that had long championed the right to free abortion. For the RFSU it was unthinkable that a woman should have to request an abortion because of minor abnormalities other than in purely exceptional cases, and to change the regulations for abortions in weeks 14 to 18, as the inquiry discussed, would be to reimpose on the woman 'a paternalism that after a long struggle she had finally rid herself of with the 1974 Abortion Act.' The very idea 'that once again she would be declared not to be trusted to decide a thing that so deeply impinges on her life' was offensive in the extreme. Worse, if it were possible to ban abortions for minor birth defects, the RFSU feared that it could end in a ban on all abortions where there was no birth defect. In other words, it was a direct threat to the right to free abortion.²⁵

The doctors too defended the existing abortion legislation and a woman's right to choose, even when the reason was the foetus's condition. This was in line with current rules, and 'all our other legislation in the field of healthcare is predicated on it being the adult who has to take decisions.'²⁶

With few exceptions, the right to free abortion thus went unchallenged by the debate about prenatal diagnosis. But many expressed restrictive views about access to prenatal diagnosis, and called for

vigilance about the technology's ethical and social consequences, and the importance of greater support for people with disabilities and their families.

Freedom of research and its consequences

Throughout the debate on prenatal diagnosis, new research findings and methods were published. This, combined with medical experts' hopes that in the future even more diseases and conditions could be diagnosed and that some treatment in utero would be possible, meant that terms such as foetal medicine, foetal therapy, and foetal surgery were introduced into the debate, largely to argue that prenatal diagnosis was not merely a question of birth defects and abortion. Existing fears persisted that such developments might have undesirable effects, especially in negative views of disability and the pursuit of 'perfect children'. The issue of research funding and whether it should be regulated was therefore part of the debate about prenatal diagnosis. The National Board of Health and Welfare's report acknowledged that independent research would lead in directions which, for a variety of reasons could have no application in society, and asked whether the applications or the research itself should be controlled in any way (Socialstyrelsen 1982, ii–iii). This part of the debate reflected an awareness that knowledge production in prenatal diagnosis was associated with strongly held values and norms.

Medical experts and researchers, naturally enough, opposed controls on research: the positive effects of prenatal diagnosis outweighed even the ethical problems posed by new knowledge and techniques.²⁷ Any attempt to control independent research would be unfortunate. Instead, what was needed was preparedness to manage the social and ethical problems that arose.²⁸ The disability movement, meanwhile, had a more restrictive stance. It was widely felt that resources should be channelled to research on the prevention and treatment of birth defects—to foetal therapy, in other words. Many also pointed to the importance of research and measures that made it possible for people with disabilities to

live in the community. Few opposed the idea that research should be independent, but many were critical of the lack of reflection and democratic discussion about its practical implications. This was the view of the Swedish Association of the Visually Impaired, among others: ‘We find it horrifying that such important research as lies behind prenatal diagnosis can be developed and put to practical use before society’s decision-making organs even have the chance to evaluate it and decide.’²⁹ Medical knowledge production should not be allowed without in-depth, democratic discussions about the possible consequences when that knowledge is transferred from the laboratory to the clinical setting. As these comments demonstrate, what was asked for was a democratic conversation, a form of public engagement with science (Irwin et al. 2013; see also Lindh in this volume), where knowledge was not only translated between different contexts, but also subjected to discussion, criticism, and reflection.

Conclusions

This chapter examines the new interpretations and understandings of prenatal diagnosis when it was translated from the medical and clinical context to the public sphere. The public debate was influenced by several movements of the day—the disability movement, the women’s movement—and also by enduring historical trends in views on health and disease, normality and deviation. The early medical discourse, which acknowledged the opportunities to reject fetuses diagnosed with genetic diseases and chromosomal abnormalities, thus reducing suffering and increasing the proportion of healthy children, was challenged by the debate about human dignity and everyone’s right to live an equal and dignified life. Soon the complexities accelerated as the debate opened up to include everything from ethical issues to political problems, and ultimately whether there were reasons to limit prenatal diagnosis in practice and to impose restrictions on the existing abortion legislation, which, after long investigations and discussions, had been passed just a decade before.

That there were deep reservations about a new, far-reaching technology during its introduction was not in itself strange. According to Jasanoff (2004), this stage, when the social order of technology has not yet stabilized, is when it is usual for conflicts over its interpretation, values, and standardization. Questions, debate, should be thought an essential element in the stabilization of complex technologies. For society to think knowledge and technology legitimate, then, neither can be decoupled from the values and norms in which they are produced and applied. In terms of co-production, the debate about prenatal diagnosis thus was a very necessary stage if this technology was to become part of the social order. Various actors—experts and representatives of different organizations—participated in the debate, which ranged over all the arguments about prenatal diagnosis, within the framework of key discourses that operated in accordance with their own logic and values.

In Sweden the debate about prenatal diagnosis did not lead to a change in the right to abortion. That right, like confidence in the woman's right to choose, was firmly rooted in the political discourse of the 1974 Abortion Act *and* in the medical discourse, and the practice of prenatal diagnosis was stabilized around these discourses. However, because of the official inquiries and discussions, there was a growing emphasis on the voluntary nature of prenatal diagnosis and the importance of women being given detailed, factual information, along with information about societal support to children with disabilities. Medical facts were not enough, information about prenatal diagnosis had to include its social and psychological aspects (Socialstyrelsen 1986). However, the highly charged and normative issues of the right and ability to choose foetal traits, would return in the following years as new medical knowledge and new technologies developed in genetics and reproductive medicine. The debate about prenatal diagnosis shows the importance of reflecting on this knowledge and its applications at an early stage. The social order it gives rise to will influence not only how the application of research is regulated, but also the conditions for future knowledge production.

Notes

- 1 This chapter was made possible by grant 2012–01048 from the Swedish Research Council for the project ‘Better humans or reduced suffering? Historical perspectives on medical genetics and genetic counselling, 1950–1980’.
- 2 The eugenics movement was found in many parts of the world, see Bashford & Levine 2010.
- 3 The Sterilization Acts in force between 1935 and 1975 permitted sterilization without consent in certain situations. Roughly half of all sterilizations in the period were voluntary, but equally in half of cases there was coercion, pressure, or outright force. Coercion was most prevalent at the start of the period (SOU 2000:20).
- 4 The indications for abortion in the 1938 Act were medical, humanitarian, and eugenic. In 1946 a socio-medical indication was added, and in 1963 serious foetal defects.
- 5 The Swedish National Board of Health and Welfare was the government agency responsible for social services, public health, and the health service.
- 6 Riksarkivet (Swedish National Archives) (RA), Stockholm, Socialstyrelsens arkiv, SN2, Sjukhusbyrån, 5E1:191, Kjessler, Lindsten, Zetterström till Socialstyrelsen, 12 Jan. 1972.
- 7 In eighties culture, images of foetal development had been established as a genre of their own, largely because of Lennart Nilsson’s acclaimed *Ett barn blir till* (1965, *A child is born*) which ran to several editions (Jülich 2015). It was launched as a book about foetal development and practical advice for pregnant women, but the complex issues of prenatal diagnosis, birth defects, and selective abortion were hardly mentioned—it was first published before the advent of prenatal diagnosis, and the second revised edition of 1976 referred to it in passing. Neither the right to an abortion nor selective abortion was mentioned. However, Nilsson’s detailed colour photographs of the development of the foetus from fertilized egg to newborn baby contributed to the idea that the foetus had personhood. The images were in some contexts used to argue against late abortions in particular (Jülich 2017).
- 8 The motion was referred for consultation. Consultation responses were received from the National Medical Research Council, the Swedish Medical Society, the National Board of Health and Welfare, and the universities’ medical and legal faculties. The Parliamentary Committee on Employment and Social Affairs recommended the motion be denied, and it was duly rejected by Parliament (Riksdagens protokoll 1972:127).
- 9 RA, Socialstyrelsens arkiv 1968–1981, SN1, Medicinalbyrån, E1:561c, Föreningen utvecklingsstörda barn (Association of Mentally Handicapped Children), Remissyttrande över Socialstyrelsens rapport *Fosterdiagnostik: Rapport från en av Socialstyrelsen tillsatt expertgrupp* 1982 (hereafter Remissyttrande).
- 10 RA, Socialstyrelsens arkiv, 1968–1981, SN1, Medicinalbyrån, E1:561c, Handikappförbundens centralkommitté (Swedish Disability Federation Central Committee), Remissyttrande.
- 11 RA, Socialstyrelsens arkiv 1968–1981, SN1, Medicinalbyrån, E1:561c, Synskadades Riksförbund (National Association for the Visually Impaired), Remissyttrande.
- 12 The synod brought together all the Swedish bishops of the Church of Sweden, the Lutheran state church.
- 13 Behind the report were Erwin Bischofberger DD SJ, Professor Holsten Fagerberg (Department of Theology, Uppsala University), Professor Gustav Giertz (Delegation for Medical Ethics, Swedish Medical Society), Sven Hemrin ThD, Professor

- Jan Lindsten (Clinical Genetics, Karolinska University Hospital, Stockholm), and Anne-Marie Thunberg LTh.
- 14 RA, Socialstyrelsens arkiv 1968–1981, SN1, Medicinalbyrån, E1:561c, Föräldraföreningen för hjärt- och lungsjuka barn (Swedish Heart and Lung Association's Parents' Association), Remissyttrande.
 - 15 RA, Socialstyrelsens arkiv 1968–1981, SN1, Medicinalbyrån, E1:561cRA, Socialstyrelsens arkiv 1968–1981, SN1, Medicinalbyrån, E1:561c, Svenska Läkaresällskapet (Swedish Medical Society), Remissyttrande.
 - 16 RA, Socialstyrelsens arkiv 1968–1981, SN1, Medicinalbyrån, E1:561c, Svenska Läkarförbundet (Swedish Medical Association), Remissyttrande.
 - 17 There had never been any question of screening all pregnant women using amniocentesis. However, AFP screening was trialled by taking blood samples from pregnant women in some health regions. The test was relatively simple and inexpensive, and indicated if the foetus had a neural tube defect. There was a degree of uncertainty concerning the test, though, and in some cases it had to be followed up with other tests such as amniocentesis.
 - 18 RA, Socialstyrelsens arkiv 1968–1981, SN1, Medicinalbyrån, E1:561c, Föräldraföreningen för hjärt- och lungsjuka barn och ungdomar, Remissyttrande.
 - 19 RA, Socialstyrelsens arkiv 1968–1981, SN1, Medicinalbyrån, E1:561c, De handikappades riksförbund (National Association of the Disabled), Remissyttrande.
 - 20 When the National Board of Health and Welfare referred its report on prenatal diagnosis for consultation to a large number of organizations and government authorities, the women's associations were noticeable by their absence. However, after they complained they were added to the list of official consultation bodies.
 - 21 RA, Socialstyrelsens arkiv 1968–1981, SN1, Medicinalbyrån, E1:561c, Sveriges socialdemokratiska kvinnoförbund (Sweden's Social Democratic Women's Association), Remissyttrande.
 - 22 RA, Socialstyrelsens arkiv 1968–1981, SN1, Medicinalbyrån, E1:561c, Fredrika Bremerförbundet (Fredrika Bremer Association), Remissyttrande. The core mission of the non-partisan Fredrika Bremer Association, one of Sweden's oldest women's organizations, was gender equality.
 - 23 RA, Socialstyrelsens arkiv 1968–1981, SN1, Medicinalbyrån, E1:561c, Vänsterpartiet kommunisternas kvinnopolitiska utskott (Left Party Communist Women's Political Committee), Remissyttrande.
 - 24 RA, Socialstyrelsens arkiv 1968–1981, SN1, Medicinalbyrån, E1:561c, Kristen Demokratisk Samlings Kvinnoförbund (Christian Democratic Women's Association), Remissyttrande.
 - 25 RA, Socialstyrelsens arkiv 1968–1981, SN1, Medicinalbyrån, E1:561c, Riksförbundet för Sexuell upplysning (Swedish Association for Sexuality Education), Remissyttrande.
 - 26 RA, Socialstyrelsens arkiv 1968–1981, SN1, Medicinalbyrån, E1:561c, Svenska Läkarförbundet, Remissyttrande.
 - 27 RA, Socialstyrelsens arkiv 1968–1981, SN1, Medicinalbyrån, E1:561c, Svenska Läkaresällskapet, Remissyttrande.
 - 28 RA, Socialstyrelsens arkiv 1968–1981, SN1, Medicinalbyrån, E1:561c, Svenska läkaresällskapet, Humangenetiska sektionen (Swedish Medical Society, Human Genetics Section), Remissyttrande.
 - 29 RA, Socialstyrelsens arkiv 1968–1981, SN1, Medicinalbyrån, E1:561c, Synskadades Riksförbund (Swedish Association of the Visually Impaired), Remissyttrande.

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