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Chapter 19: Fetal surveillance

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## **Chapter 2 - FETAL SURVEILLANCE**

### **ABSTRACT**

This chapter will challenge accepted opinion on fetal screening and ask the reader to explore the wider, covert issues related to the production of human beings. Eugenics and politics will be discussed in attempting to highlight some of the reasons for the availability and eventual outcomes of screening. This chapter will consider the acceptance of tests upon the fetus using the ideas mainly of Foucault and Parsons, for sociological interpretation. An explanation of the social influences upon the individual and the organization will lead the reader to the possibilities for the future. These theories are applied to practice.

The chapter asks the practitioner to explore why screening is adhered to routinely. It asks who is in control of the process – the woman or the doctor and what is the actual purpose of screening, is it to create a uniformity of human beings or reduce suffering? It briefly asks the moral questions of whether the fetus is entitled to life or is society at liberty to choose a suitable commodity in the form of a child? It demonstrates that women, though at the centre of the screening process, have little say on screening and even less say on the outcomes.

### **Introduction**

The fetus is open to the perfect system of surveillance which is one that observes the silent body of the non-consenting fetus, the body that cannot object or eagerly participate (Foucault, 1973). Its mother, who is obeying social norms, or accepted practice, sees the surveillance as 'normal'. The question of normality is explored within this chapter and reaches the conclusion that it is a social convention. It has no meaning other than it is what is happening to the majority of people. Normality knows no boundaries and society can push its meaning in any direction. It is only morality that puts a stop to the proceedings.

## **What is surveillance?**

Surveillance, simply defined, means nothing more than keeping a close eye or the definition according to Collins dictionary (2015) is “close observation or supervision maintained over a person, group, etc, especially one in custody or under suspicion”. The word may conjure up images of Closed Circuit Television (CCTV) within shops and other public places. The idea of ‘Big Brother is watching you’ has less meaning today than when Aldous Huxley wrote *Brave New World*, which was published in 1932 or George Orwell’s *Nineteen Eighty Four* which was published in 1949. It is the age of technology, machinery and gadgets. People have been subsumed to the mechanistic era and have integrated ‘Big Brother’ as part of their existence. It has become normal and therefore is no longer seen or acknowledged as untoward. The maternity contract between hospital providers and users may be said to have the same implicit message.

Fetal surveillance may be considered to be overrated because it would be negligent and untrue to suggest that we have the technology to prevent fetal ‘abnormalities’. Yet somehow the public are led to believe this is possible and they have the expectation that this will be the result if they attend antenatal appointments. If the system fails them, often litigation or revenge is the next step. This presently is the system of fetal surveillance. Is this desirable? Should society be free of so called ‘abnormalities’? The control over genetics is now with the scientists, doctors, insurance companies, medical suppliers and the government.

## **What are the consequences of fetal surveillance?**

Fetal surveillance has enhanced the personal blame culture of the materialist world. In other words the individual is directly responsible within a world where monetary profit is a priority. Because the fetus with ‘abnormalities’ can be destroyed there is a social expectation that the mother will take the responsibility to do so. The popular culture is one

where facilities and resources to care for the 'disabled' are reducing and there is a social stigma and stereotype that exists around disability. The fetus can thus become a commodity and it depends on surveillance if it is to be accepted or rejected. Parenting for a child becomes conditional until the quality is approved through technology. Mothers often wait to let others know they are pregnant – just in case there is 'something wrong with the baby'. People, who include mothers and practitioners, are now secondary in the technological process.

### **The emergence of surveillance**

Foucault (1973) considers that medicine has moved away from listening and seeing to the three dimensional examination involving the physical, technical and laboratory. Classically, the doctor would listen to the patient and base the diagnosis on their 'story'. The treatment would be based on the traditional fifteenth century diagnosis of 'humours' which included 'blood', 'black/green bile' or 'mucous'. Finally, with the introduction of the post-mortem into the medical school curricula, the doctor could discover the body away from the patient. Post-mortems moved life, disease and death to a technical arena (Kelly, 2009). The doctor learned about non-living tissue; tissue that could not tell its 'story' and tissue that was abstracted from life. This often is the place that doctors start their careers today.

The three dimensional examination takes on objectivity, as the doctor does not have to be influenced by the patient. It becomes truly objective when the specimen can be removed from the patient, tested in the laboratory, whereby a diagnosis can be made without the patient ever being present. Align this with the fetus under the ultrasound scan, the fetus being the specimen observed. Tissue or fluid can be removed; the specimen has no choice and no say. The diagnosis, on this specimen often leaves two choices, one of life and the other, death.

Foucault (1972) would liken fetal surveillance to the Panopticon - the perfect system of surveillance. He takes his thoughts from the model of a prison that Jeremy Bentham described in 1786 (Brunon-Ernst, 2012). This is an eight sided building with two windows to each cell. The prison warden is able to view each prisoner from a central area. The light from the window would mean that the warden could view each prisoner, but the prisoner could not see the warden. The warden could stand in one place and view those all around. Foucault called this 'the gaze', where everyone could be viewed from an advantage point. He saw that hospitals and schools, as well as prisons have been built to incorporate 'the gaze' and he called this institutional surveillance. The nurse, in the hospital, could view everyone from the middle of a nightingale ward; the teacher, in schools, could gaze upon the pupils in their rows from the podium. The patients or pupils, though, did not have the same vantage point as the nurse or teacher in that they could not gaze upon everyone from their location in the room.

The purpose of 'the gaze' is to ultimately reduce deviancy, through self-conformity. Consider a prisoner planning an escape but he does not know when he is being gazed upon. Foucault calls this mechanism that produces conformity through observation, the 'Disciplinary Power'. Non-conformity is the punishable offence which the exercise of disciplinary power seeks to correct (Larson, 2014 p50).

Society itself utilizes the Panopticon and certainly, with the use of CCTV, laser scanning in shops and paying with credit cards, everyone is being surveyed and gazed upon. *"A gaze which each individual under its weight will end by interiorising to the point that he is his own overseer, each individual thus exercising this surveillance over, and against himself"* (Foucault, 1972:155)

The gaze is thus turned in on the mother herself and consequently she accepts self-discipline or conformity (by attending antenatal appointments and abiding by the hospital protocol). Surveillance has made it possible to

change medicine from being involved with sickness alone to know the potential to discover abnormality. This has consequences such as blaming the victim, in this instance, the mother for the creation of a baby which is socially unacceptable (Page & McCandlish, 2006; Shields & Candib, 2010).

The message in health promotion is that health deviance can be avoided and the potential for choice is given to the mother. Beech (2005) suggests that choice is an illusion because the mother is making a choice from a restricted hospital menu. The covert choice from social and technological pressure (to abort an 'abnormal' fetus) is put upon the mother (Brock, 2010 p157). The mother then considers whether she will devote her life to caring for a handicapped child, in the midst of social disapproval; or whether she will destroy its life?

### **Who is making choices?**

The gaze is extended into all areas of life, for instance, the male gaze upon the female body. Males have culturally developed an 'appetite' for certain bodily characteristics by gazing upon models. Females, on the other hand, on seeing the same media propaganda aspire to copy the body image so that they too will be gazed upon. The rise in cosmetic surgery supports the notion that people are aiming to be similar (Heyes & Jones, 2009). The gaze is so strong that society is trying to manipulate its, so-called, health, with the aim of adjusting human beings to an established norm. Looking alike appears to boost an individual's ego (Nash, 2012). The way this is achieved is through the use of machinery, technology and gadgets. Consider why people have a membership for a gymnasium to work out, buy into the latest trend of dieting, pay for surgery (lipo-suction, gastric band) and so on (Richardson, 2014).

The gaze will produce uniformity (thus conformity) of looks and expectations. People do not want to be considered different and they accept normative values that are supposed to make them 'fit in' (Heyes &

Jones, 2009)) However, this leads to self-punishment, when the gaze is turned in upon the self and at the extreme, it produces eating disorders, excruciating work-outs and subjecting the body to cosmetic surgery. Equally, women will tolerate pain (via an amniocentesis or vaginal ultrasound scan, for instance) in order to gaze upon the fetus. Screening is seen as demanded by women themselves. The reality is that the choices women make are socially created as well as socially constrained.

When the gaze is applied to the fetus it will be possible to not only reject the sex of the child but also their height, weight, eye, hair and skin colour. Again, this will achieve uniformity. If this appears abhorrent consider this. The Orthodox Church in Cyprus, prior to marriage, asks couples to produce a certificate to say that they have been tested and counselled on their thalassaemia status (Idler, 2014 p195). The church will only marry couples who produce these certificates, on the premise that they will use prenatal diagnosis and abortion. The church does not condone abortion for other reasons. The point is this, thought originates in culture (Foucault, 1974:50) and then it can become normalized and accepted.

The pregnant woman conforms by attending antenatal clinics, where the fetus can be gazed upon. The woman knows that the fetus is being surveyed but does not know everything that is seen. The technician who has this information therefore wields power. Power allows people to exploit others for their own gain (McKenzie et al, 2014).

The Marxist notion is that women will reproduce according to the needs of capitalism; therefore the woman will be alienated from the end product; just like the car assembly worker who only has a small part to play in the car's production. She is the commodity that serves the political and economic needs of that society.

*The biological traits of a population become relevant factors for economic management and it becomes necessary to organize around them an*

*apparatus which will ensure not only their subjection but the constant increase of their utility (Foucault, 1972:172).*

Materialism is promoted by capitalism. Machinery manufacturers continuously create even more 'precise' equipment such as with ultrasound, which is welcomed by the maternity system.

It can be seen that the technology, which is established to further the capitalist economy, holds a powerful footing. The problem with power is that it can be belittled or removed and therefore to prevent this from happening it becomes important to subordinate women with the antenatal system. This then creates a continuous struggle to develop 'secret' knowledge (which is expressed through the manipulation of machinery, technology and gadgets) (Scambler, 2005). Take for instance an ultrasound scan examination of a pregnant woman; what is observed is a subordinate woman lying, often silently, looking at the screen, hoping to get pleasure by seeing her 'normal' baby. Subordination is evident, not just in hospitals, but in every area of society where power is to be maintained and this includes even the micro-structure of a family (Fahy, 2008).

Foucault (1972) recognizes that knowledge creates and results in domination. He (1972, p119) acknowledges that, for example, the ultrasound scan will produce new knowledge which in turn produces discourse – that is current thinking which is esoteric and not understood by the general public. This authoritative knowledge is usually amongst professions and it is this discourse which increases the body of knowledge through the medium of language. Foucault (1974, p87) simply says that language is the basis of knowledge. Language "is a necessary medium for any scientific knowledge that wishes to be expressed in discourse" (1974, p296).

Without language the dis-ease could not be labelled and therefore could not be treated or obliterated. The label given allows the doctor to reason



and create what is socially acceptable or not. Thus, if women questioned the dis-ease they would be driven into subordination by the act of the doctor's reasoning (Abrams, 2015). The reasoning process will validate surveillance which will have included machinery, technology or gadgets (which are venerated as the truth).

The creation of knowledge, which often is an agreed opinion, gives power and status, not to the specimen that was gazed upon, but to those that created the label to describe what was gazed upon. The subjects of truth, knowledge and what is considered right are all creating power. It is power that creates what is then accepted as truth (Haugaard, 2012).

The human genome project creates the perfect objective gaze because "in order to know the truth of a pathological fact the doctor must abstract the patient" (Foucault, 1973 p 8). Danaher & Schirato (2000:50) inform us that "one of discipline's concerns is with producing docile healthy bodies". Ultimately, the production of designer children will be possible if this trend is continued, thus creating children that conform to ethnocentric ideas of normality and desirability.

Foucault (1973) explains that at the end of the eighteenth century the life/death continuum started to change from being normal to abnormal. The only abnormal death prior to this time resulted from murder/war. Birth and death now happen mainly in hospital. The hospital depicts Max Weber's 'ideal type' of institution (Thornton et al, 2012), that is a rational, hierarchical, bureaucratic structure, whereby everyone performs a unique function/skill for a minimum cost to the organization. To ensure efficiency everyone is overseen and thus will be subordinated to some part of the hierarchy - "The hierarchy established to provide a progression towards the more complex and the less exact" (Foucault, 1974, p246). It can be seen from this that allowing birth/death to happen naturally can overturn the 'ideal type', therefore both ends of the continuum are manipulated with the help of machinery, technology and gadgets. This change is seen as normal (Danaher & Schirato (2000).

Normality is therefore socially constructed. The word originates from the statistical 'norm', which is constantly changing. Take for instance the number of women having an ultrasound scan in pregnancy 30 years ago. This would not have been deemed a 'normal' routine practice. Today, all women processed through the hospital maternity system are offered routine ultrasound scans; it is deemed 'normal' for pregnant women to have an ultrasound scan. Normal is very different from natural. No woman would physiologically (in nature) have an ultrasound scan. The scan has developed as part of scientific medicine and the use of machinery, technology and gadgets.

Consider the difference between a natural and a normal birth. What is now conceived as normal cannot be termed natural. Most normal births will have occurred as a result of the use of machinery, technology and gadgets. Equally, death that has occurred with the use of technology involving drugs cannot be conceived as natural. This is easier to see in the fetus than in the adult. For instance, injecting potassium chloride into the fetal heart with the intention of committing fetocide, some might argue, is not different to the morphine that is offered as 'pain relief' to the terminally ill adult.

The changing social view of normality may originate in the scientific or technocratic community. Doctors define what is a 'normal' or 'abnormal' baby. A technological diagnosis is made through chromosome analysis, for instance, and if the result is 'abnormal' the doctor offers death of the fetus to the parents. This is termed a "therapeutic abortion"; but for whom is it therapeutic? A similar option would not be given to parents if a doctor deemed the baby to be 'normal'. Foucault (1972, p177) considers "the hospital is more the seat of death for the cities where it is sited than a therapeutic agent for the population as a whole". The dominant ideology of informed choice purports to look at all the options (which medicine has chosen to offer) and yet the options appear limited when that of

termination of the pregnancy dominates the conversation. Could this be the present day form of eugenics?

## **Eugenics**

Historically, eugenics might have been said to originate to prevent the higher social classes being burdened by 'social problems'. Eugenics is used to apply genetics to gain desirable inherited characteristics (Glad, 2006). Simply put it has been used to pair couples for breeding and to sterilize the poor, those with unacceptable social behaviours (for instance women who bore children when not married) and those requiring support from outside of their families (Moss et al, 2013).

Marie Stopes, one of the original eugenicists, opened Britain's first birth control clinic in 1921 and wanted to legalise sterilisation for the "hopelessly rotten and racially diseased" (Dhout, 2009, p 84). When she died the Eugenics society benefitted from her estate (Dhout, 2009). Margaret Sanger, also a eugenicist, was a founder member of the Planned Parenthood Federation. But it was Francis Galton, a statistician, who founded the Eugenics Society and first used the term eugenics in 1883 (McCavitt, 2013). He developed an interest in obtaining "good human stock". He noted that farmers and horticulturists could obtain a permanent species of animal or plant and saw a normal development of applying this to human beings. He thought that social deviance at the time (poverty, alcoholism, prostitution and crime) could be abolished through selective breeding. This appealed to many of the middle and upper social classes who wanted to promote their own culture and values (McCavitt, 2013). Many eugenicists believed that contraception should be withheld from the upper social groups, who they wanted to reproduce (O'Brien, 2013).

Thus developed the Eugenics Society, which included members such as Charles Darwin's nephew, Leonard Darwin, who in 1926, suggested ways of getting rid of the inferior by "the lethal chamber, murder, segregation by

imprisonment, confinement and supervision, sterilization and family limitation by contraception or abstinence". Winston Churchill (1874-1965) was said to want "compulsory sterilisation of the feeble-minded and insane classes" (Dhout, 2009 p 85). If the social ills at that time were referred to the individual's inheritance then no social policy was necessary to engage spending from the public purse (Phelan et al, 2013; Grekul, 2008). Sir Keith Joseph reiterated this thinking when he made a public speech in 1972 referring to genes reproducing social ills (Welshman, 2012).

Publishing one's thoughts was considered 'normal' in the 1920's and the notion of "P.C." (political correctness) certainly did not prevail at the time. Therefore, it is easier to see how Adolf Hitler and his ideas of producing the Aryan race did not cause a public outcry. The following historical eugenicist example will possibly enlighten as to where current day antenatal surveillance practices may lead.

Eugenics and Racial Hygiene were introduced into the medical school curricula, in Germany by 1933. It could be argued that Nazi racial policy originated from the scientific community and created the Holocaust (O'Brien, 2013). Galton introduced pedigrees (for humans) into England prior to this time but Nazi Germany introduced them under the race laws. On 14<sup>th</sup> July, 1937 the sterilization law was passed for the prevention of genetically diseased offspring and hundreds of thousands of people were sterilized under these laws. Euthanasia, in gas chambers, was introduced legally for the mentally ill, handicapped and infirm; which meant that residential homes and hospitals could be closed down. The war years brought mass extermination of human beings to prevent their reproduction. This potted history misses much but allows the consideration of the 'slippery slope'.

Post World War II the majority of the public saw eugenics as abhorrent (Mackellar & Bechtel, 2014). The word eugenics was interpreted as racism in the United States. The eugenicist publications were changing

their name to genetics in the title and interestingly the first genetic advisory clinic in Britain was commenced in 1946. It used pedigrees as part of the history taking process, as do genetic counsellors of today.

Japan's National Eugenic Law (1940) was revised as the Eugenic Protection Law (1996). These laws enforced people with disabilities to be sterilized so that reproduction of their genes could cease. 16,520 people were sterilized because of these laws between 1949 and 1997 (Kato, 2010, p187). The Alberta Sexual Sterilisation Act (1928) remained in law until 1972. 2,500 people were sterilised as a result of this law. Sterilization was enforced for those who obtained low scores on intelligence quotient testing or were in-patients of psychiatric hospitals (McCavitt, 2013). Just prior to this Act being passed scientists linked "feeble mindedness and social problems" together (Grekul, 2008 p249).

Fetal Surveillance took on a different meaning in 1967 since it was the first time that abortion could be offered legally. Even though amniocentesis was a technique the medical profession were familiar with prior to this time, it did not become available to pregnant women until 1967, when a fetus deemed to be 'abnormal' could be terminated. The procedure was termed a therapeutic abortion. Therapeutic for who - the fetus or society?

Eugenics is selective breeding to produce "the best" children possible (Bennett, 2009, p265) and includes a preference for a specific type of child for example, a male. This is in opposition to using sex selection for the prevention of a sex linked disorder. In the former instance it could be viewed that there is little regard for the life of females. Once there exists a gender bias then there is a suggestion that one must be better than the other. Parents may also seek out other characteristics such as athletic ability, intelligence or physical prowess. Reproducing children that are considered "the best" is socially constructed for a particular society and is the new eugenics (Sparrow, 2012).

Hauss & Ziegler (2008, p756) tell us that eugenics is used as a social policy to produce individuals that are desired by the pre-requisites of that society whilst at the same time abolishing social problems and individuals that need social support. Dixon (2011, p38) explains that despite having the explicit aim of getting rid of abnormalities with fetal surveillance there remains a “risk of birth defects” and the results of the screening are not always accurate. There is also the concern of producing the aberrant gene with genetic engineering. Mendel (1822-1884) pointed out, by hybridization of species of peas, that regardless of the use of precise techniques of genetic manipulation there will always be a mutation (recessive gene) (Bareja, 2013).

Abnormality is a social construct. Dissonance is clearly present with the public outcry that resulted when a deaf couple wanted a sperm donor to guarantee that they would have a deaf child and yet there is no such outcry when another couple request an egg donor with a high intelligence and athletic features (Sandel, 2007). It could be argued that parents have a moral duty to provide the best life possible for their children which is very different from producing the “best children possible” (Bennett, 2009, p273). The “best children” are a social construction.

The human genome project could be said to be the continuation of eugenics. It identifies all the material in the twenty three pairs of chromosomes and gives information about a person that is unknown and unseen to anyone. It was Watson & Crick, in 1953, that discovered the double helix structure of DNA and this initiated the Human Genome Project which was completed in 2003 (Phelan et al, 2013). It is now known that there are three billion base pairs of human genetic make up (Gaffney et al, 2012). The question remains as to what will be done with genome information. Commercially it will be expensive to buy the genome on one individual. It is thought that some employers and insurance companies would be willing to pay the price in order to avoid a ‘bad’ risk (Klitzman et al, 2014). Insurance companies may choose not to insure ‘bad’ risks and people with ‘good’ health may decide they do not need the

insurance. The premiums would increase dramatically so that people requiring insurance may not afford it (Joly et al, 2014). James Dewey Watson (Nobel prize winner) stated that he wanted to alter the human genome in order to improve human beings (Dhout, 2009 p 85).

### **Ethical considerations**

In the UK, the fetus has no legal rights as a person and therefore cannot have full moral status (Baker, 2013). Today, with the 1990 Human Fertilization and Embryology Act, termination of pregnancy can be carried out at any gestation if there is a serious fetal handicap.

Abortion for fetal abnormality cannot ethically be different to paediatric euthanasia (Farmer, 2008). Currently, paediatric euthanasia is not a 'normal' or legal procedure, whilst fetal euthanasia is an acceptable and legal practice. Since January, 1995 the government, in China, have forbidden couples with a serious genetic disease from having children, and this is enforced through abortion (Sui, 2010). This reinforces the social conventionalist view that it is humans that determine normality, not nature.

Destruction of life to rid 'abnormalities' is not new. It can be traced back to the classics. Aristotle suggested that the ideal legislation, in his politics, was to destroy deformed infants. Plato, not only agrees with Aristotle, in 'The Republic' but adds that the destruction of babies, who are the result of 'unfit' parents, or produced by parents past the ideal childbearing age, would also be beneficial to society (Combe, 1840).

Analysing the reasons for fetal surveillance poses two questions, is its purpose to remove genetic defects or to produce individuals with more desirable qualities? Given that fetuses have been killed because they have cleft lips or are female, for instance, it may be that of the latter. From an ethical viewpoint it could be argued that removing pain and suffering from the potentially disabled child through prevention of their life

is beneficence. With this comes the belief that no harm is caused. On the other hand, a child born disabled could sue her/his parents for a tort of wrongful life. None of this, though, can be enforced on moral grounds (Hall, 2014).

Are parents making the decision of what child is genetically worthy of life, or is it the doctor's choice, on behalf of society? The doctor acts as the detective using the technical screening process within eugenic principles, of enforcing abortion through social control. Leadership, as in the case of the doctor, can only be ethical when it is based on altruism and not egotism (Shale, 2012).

The Abortion Act (1967) however reiterates that the abortion is the doctor's choice as two doctors have to sign it – not the woman (The Abortion Act, 1967). If women's autonomy is to be respected then medicine cannot be paternalistic. Autonomy is a person's ability to make her/his own decisions and act upon them. In order to be able to fulfil the individual requirement of autonomy, informed consent is essential before submission to any medical procedure. This is impossible within the confines of scientific medicine where there is no room for manoeuvre in consideration of an individual's preferences. Scientific medicine is quantitative and depends on machinery, technology and gadgets. The midwife may consider that she is giving enough information for or against any procedure and yet may inadvertently be professionally steering the woman to accept the procedure. The woman's perception of the information may not be as the midwife sees it. The woman may unknowingly comply or feel she is being coerced into acceptance. Women who 'choose' the option of abortion, freely, will also know that they are willing to accept responsibility for this decision, which would include the possibility of sterility.

The technology behind surveillance cannot be neutral. There is an argument that would suggest that the technology:



1. From a feminist point of view is sexist
2. From a disabled rights point of view is ableist
3. From a race relations point of view is racist

1. Some Feminists see technology as abusing women and their bodies. Women tend to accept the procedural norms of the maternity system, often not questioning nor receiving sufficient information (Fahy, 2008). Information has to be given to avoid litigation but enough can be withheld to ensure compliance. Women are coerced (by the doctor, their family, the genetic counsellor or the midwife) to have an abortion for fetal abnormality, whilst believing that they have made the choice themselves. The technology can be seen as a form of harassment which is formulated by the medical profession against women (Prochaska et al, 2015).

2. Disabled Rights organizations acknowledge that due to the increase in abortion there is a greater intolerance of people, especially children, with disabilities. There are dwindling resources to support disability in society and, with a gradual removal of disabled rights, there is less likelihood of trying to find a cure (Dixon, 2011). This is probably the result of cause and effect. Prenatal diagnosis and abortion are cheaper in most cases than financially supporting an 'abnormal' person.

Disability is seen as undesirable, whilst able people are seen as desirable, therefore by implication, people who already exist with a disability are also undesirable and thus a lower value is placed on their lives (Bennett, 2009). Prenatal diagnosis and selective abortion are juxtaposed with an increasing number of people surviving with 'abnormalities' such as diabetes or cardiac disease. They would otherwise have not been conceived, been miscarried, been a stillbirth or died in life. These people now exist because of the efforts of technology. The undesirability of disability is incongruent when society sends able-bodied people to wars to be killed or maimed and thus become disabled.

3. Racism arises from the issue of trying to narrow the gene pool or promote a certain genetic stock, in principle suggesting that every other resulting human being is unworthy of human status (MacKellar & Bechtel, 2014). Eugenics is producing a desirable phenotype or genotype which is different from what parents would choose (thus overriding individual choice). This is racist. What does this say about a society that will not tolerate differences and is there not a moral duty to let all humans live (Wilkinson & Garrad, 2013)?

New reproductive technologies have taken the ethical argument and one of fetal surveillance a step further. Does the doctor have a moral duty to place the healthiest blastocyst into the woman's uterus, when he has a selection of different growing fertilised ova to choose from in vitro? The doctor then has the power to destroy the other blastocysts that did not replicate their cells fast enough (MacKellar & Bechtel, 2014). Furthermore the NHS will not put forward everyone for these 'treatments' and if it does then the number of attempts offered to get pregnant are limited. On the other hand if the woman can afford a private fertility clinic there are no restrictions placed on the number of attempts she can pay for, in order to achieve a pregnancy (O'Brien & Meghan, 2009).

Medical science has contributed to genetically engineering babies, with in vitro testing for mental and physical 'defects', including the search for the 'gay' gene (McCavitt, 2013). As choosing a child's features become available it is thought that couples will start to reject the choice of a 'natural' child (Dixon, 2011). A 'natural' child has the probability of being differently abled to the eugenically engineered child which will become the social norm. Sparrow (2011 p38) asks if the common technically created children would then have a moral duty, through their taxes to care for a 'natural' child whose birth could have been avoided? Screening already is the norm and therefore parents who do not avail themselves of this service could be seen as unreasonable in law.

## Who has the power?

Talcott Parsons (1951), a structural functionalist, was clear that power was with the doctor. He recognized that the pregnant woman had an obligation to obey the doctor. Parsons considered the doctor to have social influence and this alone would ensure that patients would carry out their duties and obligations. The mother is seen to have a duty to subordinate her own interest of having a child to that of the greater interest of the society in the creation of 'normality' (MacKellar & Bechtel, 2014).

Parsons thought the woman would not be able, or competent, to make a technical decision. In fact he alludes to her subjectivity and thus irresponsibility. It is important to view this in context. Consider the 1950's, in the United States of America, and the role of women. The social expectation was that women would be mothers and housewives. Value was placed on the capitalist ethic of economic productivity, as today; hence women who were unpaid for their work derived low status and felt often disempowered. However, Parsons saw the doctors gaining the empowerment and economic reward and it is from this social context that Parsons was able to write:

*Birth and the rearing of a child constitutes a 'cost' to the society, through pregnancy, childcare, socialization, formal training and many other channels. Premature death, before the individual has had the opportunity to play out his full quota of social roles, means that only a partial 'return' for this cost has been received (1951, p430).*

Parsons, it could be argued, was a linear reductionist in that he was able to 'box everything' simply or put it in its place. All human beings were shown to have social roles, which defined their existence. He literally was able to discuss one set of human activities and shows how it would go on to affect another set of human activities. However, he dealt only with the external environmental role (or how the individual interacted in society)

and did not explore internal issues (Bolender, 2015). Parsons, before Foucault, considered the sick role as one of a disciplinary process – The sick role allowed exemption from work and other responsibilities but it came with obligations such as to seek medical help (Varul, 2010). Again, like Foucault, he recognized that there is a choice between obeying procedural norms or the alternative was that of punishment. Choice is not available when carrying out an obligation.

Parsons sees handicap as dysfunctional. It cannot fit into the scheme of society. Handicap is being labelled as 'useless' to society and therefore has to be obliterated. The human activity associated with handicap is not seen as productive to the society from a capitalist perspective, and therefore it would not set off the linear array of human activity associated with capitalism. One way of obliterating handicap is through socializing women into accepting fetal surveillance. On entering the hospital and the maternity system, it is, for the majority of women, an unspoken contract to obey procedural norms and, for Parsons, women should have no say.

The hospital is an institution of social control. Medicine can label our diseases and make them real. The technology originated, not as a result of public demand, but as a response to demand from doctors, scientists and big multi-national pharmaceutical and machinery companies (MHRA, 2008) thus promoting the capitalist ethos. Parsons might say that the institutionalization and therefore normalization of fetal surveillance means that women will find the procedure comforting and thus worthwhile. Women want confirmation of normality (Jomeen, 2010)). But if the sick role becomes normalized as the health role then the domination of the doctors will take on more importance. Alongside there will be the development of an engendering of self-interest and responsibility (thus self blame for 'abnormalities') by the woman (Page & McCandlish, 2006; Shields & Candib, 2010).

## **Prevention**

The majority of 'abnormalities' after all result from the environment not from the gene pool. Genetic disorders account for half of the 3-6% of babies born with a handicap (Fridovich-Keil, 2015). Perhaps, in an effort to thwart 'abnormality' attention needs to be directed towards the prevention of war, poverty, environmental hazards/pollutants, accidents and disease (Feil & Fraga, 2012). The capitalist economy exists whereby big multi-national companies may consider profit before health and thus handicap will result from food pollution, chemical contamination, nuclear power and the effects of acid rain on fish and so on. Policies to change employment, state benefit, housing and taxation are some areas that need to be addressed to avoid 'abnormality' in order to gain the long-term benefit in the production of healthy children.

The prevention of poverty and deprivation would be costly and have less effect on the development of political careers and personal interests. Fetal surveillance is given preference because it is cheaper than social welfare. Good nutrition, for instance, affects healthy cell production; social pressure can negatively affect immune response and thus health. Social policy to better nutritional status, housing and economic support can be ignored if the origins of 'abnormality' are cast back on the individual, as is happening in this victim blaming society. The victim blaming perspective could be used to provide an elitist model, which would make use of a person's genetic profile to determine her/his 'worthiness' for different jobs, insurance risks, reproductive mates and material wealth. Clearly, this is a huge political issue, which if tackled would need to change the ethos in society from the "I'm all right Jack" culture into developing the sense of community, which has been lost in many major cities of the world.

## **Conclusion**

Surveillance has become normalized through the ritual of maternity care. How many women go along with the ritual for fear of being reprimanded and possibly denigrated by professionals within the maternity services?

Eugenics, regardless in which century it is placed, is a reflection of the current social and political agenda for social change. The introduction of the 'welfare state' was highly acclaimed and inspirational to many around the world; it was followed by the rationalization of resources and the imperative to preserve the public purse. Fetal surveillance was introduced on the one hand to reduce children with undesirable features and on the other with a view to reducing the cost to society. Society would bear the burden of the cost of caring for those who potentially would be either unable to do this for themselves, or/and they would require the cost of ongoing care. Today instead the costs of fetal surveillance, through screening, have risen exponentially; previously a blood test would suffice and now it requires machinery, technology and gadgets. This moves money from the public purse to private multinational corporations who have used fetal surveillance as an opportunity to maximise their profit.

How many have stopped to think whether the cost actually benefits the people involved not just physically but emotionally. Screening has created an individual fear of accepting the pregnancy/fetus in case of a 'need' for an abortion. Women have received fetal euthanasia and some continue to live with the thought that they 'killed their baby'. Those who chose not to accept an abortion may live with the 'guilt' of passing on 'bad genes' and the social stigma of letting their child live.

Will the 'slippery slope' develop the continuum of what is genetically worthy based on the scientific community's opinion? Is it possible that, on the other hand, the nature of society will change from the competitive, materialist world to acceptance of diversity and investment in improving our environment which in turn will enhance the lives and health of all human beings?

### **Key Points**

- The acceptable boundaries of fetal normality are set within the scientific community

- Eugenics originated within the scientific community
- Technology originates from the needs of capitalism
- Technology can be viewed as sexist, ableist and racist
- Fetal surveillance is a process designed to select desirable individuals

## **Useful addresses**

### **ARC – Antenatal results and choices**

345 City Road

London

EC1V 1LR

Helpline: 0845 077 2290 or 0207 713 7486

Tel admin: 0207 713 7356

Email: [info@arc-uk.org](mailto:info@arc-uk.org)

Website: [www.arc-uk.org](http://www.arc-uk.org)

### **Contact a Family – for families with disabled children**

209-211 City Road

London

EC1V 1JN

Helpline: 0808 808 3555

Tel Admin: 0207 608 8700

Email: [info@cafamily.org.uk](mailto:info@cafamily.org.uk)

Website: [www.cafamily.org.uk](http://www.cafamily.org.uk)

### **SANDS – Stillbirth and neonatal death society**

28 Portland Place

London

W1B 1LY

Helpline: 0207 436 5881

Tel admin: 0207 436 7940

Email: [helpline@uk-sands.org](mailto:helpline@uk-sands.org)

Website: <https://www.uk-sands.org>

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