Chapter 1
Parental Responsibility: A Moving Target

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Abstract Beliefs about the moral status of children have changed significantly in recent decades in the Western world. At the same time, knowledge about likely consequences for children of individual, parental, and societal choices has grown, as has the array of choices that (prospective) parents may have at their disposal. The intersection between these beliefs, this new knowledge, and these new choices has created a minefield of expectations from parents and a seemingly ever-expanding responsibility towards their children. Some of these new challenges have resulted from progress in genetics and neuroscience. It is these challenges that we focus on in this introduction and volume.

Keywords Parental responsibility • Genetics • Neuroscience • Childhood • Parenting

1.1 Background

Ideas of what constitutes parental responsibility are constantly changing, under the influence of social, cultural, as well as scientific developments. A major contributor to discussions on responsibility for children is the changing landscape in the last

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century of shared perceptions of the moral status of children and their place in the family and in society. It is a relatively recent development that, at least in Western cultures, children are seen as bearers of rights as well as vulnerable members of our societies, in need of extra protection (Archard 2004) – sometimes from their own parents. From being considered cheap and expendable work force, little more than their parents' property, children have increasingly obtained legal and moral standing. In this process of progression from parent-centred accounts of parental rights towards ones in which children's rights are at least as important (Gheaus 2012), we are now leaving the familiar realm of parental duties as requiring not much more than that parents provide their children with a home, feed them, bring them to the doctor in case they fall ill, and send them to school. Today's expectations go much further than that, and social norms of what parents should do and what children are entitled to have fundamentally changed over the past decades. Parents are now held responsible for their children's cognitive and social-emotional development. Many parents feel obliged to introduce their children to various sports, have them learn how to play music instruments and one or two foreign languages from an early age. They are also being held responsible for the healthy physical development of their children, such as preventing them from becoming obese (Holm 2008). They should provide what is considered healthy foods, and are supposed to make use of educational interventions of various kinds that support children's emotional wellbeing. This does not only hold for what parents should do to improve their children's chances in life, but it holds likewise for their own behaviour and the role model that they have to offer. It has, for example, been argued that parents should not smoke in the presence of children and preferably should quit smoking altogether (Brennan and White 2007).

A much discussed aspect of parental responsibility is that of making medical decisions on behalf of children and in their *best interest* – and how this translates into practice. It is often not clear what children's best interest *is*, nor how a present interest balances against interests that a child might develop in the future. A major aspect of the discussion of what constitutes parental responsibility has to do with the appreciation of childhood. Is childhood only valuable as a transitory stage towards adulthood? Are the choices that a child may have as an adult in need of protection, even if this would mean an infringement of her current choices or wellbeing (Brennan 2014)? For example, if a child is at risk of losing her fertility, should parents safeguard her reproductive potential in case she wants to become a genetic parent later in life (Cutas in this volume)? If children are, so to speak, adults *in the making* [or *unfinished adults* (Gheaus 2015)] then perhaps their parents *do* have to prioritise at least some of the interests that children might have as adults over current interests. It is tempting to see a child's life in a historical perspective, but it is not clear that by choosing to safeguard an interest that the child does not yet have we are in fact working towards her best interests.

Moreover, respect for an adult person is often framed in terms of her autonomy, and only in exceptional cases can respect for adult autonomy be overridden by considerations of wellbeing. A child, however, is in a gradual developmental process towards autonomy and learns how to be an autonomous person by exercising her autonomy in a controlled environment. Hence, the autonomy of children, if any, can be restricted if such a restriction is deemed to be in her best interest (Matthews

1996). For example, Blustein argues that parents have a duty to respect a child's own desires in matters that are not critical to protecting the child's interests, and if they are not likely to impede the child's development (Blustein 1982). But this suggests that a child's best interest supersedes all other considerations. Often the process of medical decision-making on behalf of children goes smoothly: parents and health professionals agree on the kind of medical problem the child has and on how her condition should be best dealt with. However, any significant disagreement between parents and children, or parents and health professionals, can lead to open disputes that require a resolve of what the child's interests are, how they should be met, and who should meet them. Perhaps most notoriously, such have been the cases of Jehovah's witnesses refusing life-saving blood transfers for their children (Woolley 2005) or the cases of male circumcision for cultural rather than medical reasons (Earp 2013).

Questions regarding the scope of parental responsibility become even more acute given current new scientific findings in *neuroscience*. Controversies regarding the status of mental health disorders in children and the question whether, and if so which, children should go through diagnostic processes, complicate considerations about parental responsibility. Under which conditions and when is it appropriate to consider children to be at-risk to develop such disorders or to diagnose them? How should potential preventive interventions or treatments be envisaged? To answer these questions it makes a relevant difference whether mental health issues are seen as some kind of a brain-disease or as essentially normative interpretations of behaviour (see Bosman in this volume). Even if we agree on the fact that children with behavioural problems or mental health issues should be helped and that it is in the first instance the responsibility of their parents to seek and organize this help, as Syurina and Feron argue in this volume, how exactly parents can fulfil this responsibility varies greatly.

Progress in *genetics* also raises new questions with regard to responsibilities for children. For example, before genes and their functions were discovered, inheriting traits that run in the family was considered a result of fate rather than of specific choice. Premature death because of sickle cell anaemia, for example, has been called the 'born-to-die-prematurely syndrome' in societies affected by it (see Fayemi in this volume). With the discovery of the double helix and the many mutations associated with diseases, at first, this concept of fate was still there. As we cannot change our genes, the passing on of defective genes was seen as beyond our control. However, we can now be forewarned about a host of genetic conditions. In some cases, as that of sickle cell anaemia, this knowledge can be life-saving, in others it can make life for the child and her family tremendously easier. For example, if parents and professionals know that a child has phenylketonuria (PKU), and thus cannot metabolise certain foods, they can make certain dietary choices rather than others and thereby avoid that children will come to develop serious brain damage and mental retardation.

The possibility of detecting defective genes, in vitro or prenatally, raises important questions for parental responsibility (see also Hübel et al. in this volume). Should we choose between embryos, and if yes, how? Should we choose the embryo most likely to have the best start in life (see Herissone-Kelly in this volume;

Savulescu 2001; Savulescu and Kahane 2009)? Is the hope to create a child with the best chances in life realistic – or is this the result of an unjustifiably optimistic reliance on the impact of genetic conditions on the good life? Do the potential risks that these techniques may entail override the benefits of selecting the healthiest embryo (see Güell in this volume)? Once we *can* know our own genetic make-up, or the one of our gametes or embryos, do we have a responsibility to acquire this knowledge and act on it? If a negative outcome for children can be attributed to lifestyle choices rather than genetic causes, this responsibility is perhaps more easily attributed. Fetal alcohol syndrome is a seminal example. It is easier to blame a pregnant woman for drinking alcohol during pregnancy than to accuse a parent who unknowingly passes on a damaging mutation to the next generation. Are women morally blameworthy if their children are born with fetal alcohol syndrome or develop neonatal abstinence syndrome, and if they are, can they legitimately be pressured or coerced to stop drinking or using drugs in order to protect their children before they are born (see Dondorp and de Wert in this volume)?

The rise in knowledge about epigenetics complicates such questions even further. For example, studies have demonstrated that a diet low in vitamin B12 during pregnancy can induce problems in offspring, but also in the offspring of that offspring (Suren et al. 2013, Hens in this volume). Is a woman who has had a diet low in B12 responsible that her child is prone to becoming obese? Is she responsible for any consequence that this might have on her grandchildren? If there is a small risk that a man who smoked as a boy will cause asthma in his child many years later because of this (Hens 2017), and his child does develop asthma, is the man responsible for this outcome? The discovery of such connections between what we until recently saw as benign and private behaviours and circumstances, and (sometimes significant) effects on children or even future generations, can be baffling. It can, at the same time, invite moral judgment into areas of people's lives in ways that we may not see as justified, and it can create a temptation for policy-makers to police private lives in the name of future interests, future goods, or of the public good. All these are very important questions and risks that have to be discussed, and these discussions have to include scientists, psychologists, ethicists, and anyone else who can contribute relevant aspects.

Throughout this volume, "her" and "she" will be used when referring to adults and children in general – regardless of their gender. Unless otherwise specified, the term "parents" will be used to denote all caregivers taking up parental roles – regardless of genetic or biological connections. It will be used to denote both fathers and mothers, again unless otherwise specified. We are aware that expectations from (prospective) mothers and fathers, respectively, as well as from men and women, can differ greatly. As Purdy aptly pointed out already two decades ago, women are seen as owing more to their children before they are even mothers than anyone else owes anybody else (Purdy 1996). Perhaps an illustration of this is a court case in the US in which a child who needed compatible bone marrow to survive was denied access to his biological father's contact details (Purdy 1996, Re George 1982). In this case, not only was the man not expected to make a small effort to save the life of the child he helped create, but it was deemed unacceptable to so much as ask him. While these inequalities are increasingly being questioned and analysed in recent years, and the parental roles of mothers and fathers are coming closer together (Collier and Sheldon 2008), we acknowledge that much work still remains to be done.

1.2 Current Debates

While questions of parental responsibilities are actualised in various areas of life, the authors in this volume focus on those that are raised by findings in genetics and neuroscience. We investigate both whether there are *new* dimensions of parental responsibility that did not exist before the rise of genetics and/or neuroscience, and potential changes to the content of parental responsibilities already established (see Björnsson and Brülde in this volume). In the context of genetics, the possibility has arisen that parents select, at least partly, the genetic profile of their future child by means of, for example, preimplantation genetic diagnosis (PGD). This raises completely new questions such as whether parents have a responsibility to make use of such a technique to either avoid serious genetic diseases in their children, or maybe to enhance their 'genetic fitness' in general. In the context of neuroscience, enormous insights have been gained on the process of brain development during childhood as well as on the effects of children's environment on that development. This raises the question of whether it is part of parents' responsibility to take insights on brain development and potential adverse or beneficial environmental effects into account when having and raising children. In other words, should parents help their children train their brains in order to safeguard or even increase individual flourishing (see Horstkötter in this volume) or avoid socially deprived neighbourhoods because of potentially harmful effects on their children's brains? One could also argue that parents have a responsibility to help their children flourish and avoid their suffering even if this involves surgical intervention on the children's brain, as is the case of deep brain stimulation (see Foquaert in this volume).

What is meant by wellbeing is still under debate. A specific context in which responsibility towards future children has been extensively discussed is that of embryo selection. This context is different from that of prenatal testing, as there the responsibility is towards a specific (future) child. Indeed, embryo selection involves choosing between embryos in vitro based on chromosomal or genetic characteristics. Therefore, the question here is 'what children should there be' rather than what is good for a specific child. The concepts of *beneficence* or *enhancement* are central to this discussion. A much discussed principle in this context is that of *procreative beneficence*. According to this principle, prospective parents should pick the embryo that is most likely to have the best start in life (Savulescu 2001; Savulescu and Kahane 2009). This principle is a comparative one, and it does not prescribe that if only suboptimal embryos are available, none should be selected. It is also compatible with the exercise of parents' reproductive autonomy: parents should not be prevented from making choices even if this means choosing an embryo with a certain condition and violating the principle (Savulescu 2002).

Some authors have defined thresholds that an embryo should meet in order to be eligible for transfer to the womb. A minimal threshold suggests that there is a duty only to discard those embryos that would develop into children whose life would be not worth living because it would be filled with suffering. Others define an acceptable outlook threshold or even a maximum threshold, stating that only embryos with a very good prospect should be selected (Harris 2001; Glover 2006). Commentators have questioned the idea that prospective parents have an obligation *to select the best children*, rather than *the best for a specific child* (Bennett 2009, 2014; Herissone-Kelly 2006 and in this volume; McDougall 2005; Parker 2007). Parfit has argued that there are responsibilities to make sure that the wellbeing of the children that are born is maximized, even when this means selecting one child to be born over another or waiting for the optimal circumstances in which to procreate (Parfit 1984). This is an ongoing discussion that teases out intuitions and expectations from and of (prospective) parents when contemplating reproduction and what they should do.

In the creation of this volume and the selection of contributing chapters, we bring together perspectives relevant for the general topic. Parents, as opposed to non-parents, are considered to hold a special relationship to children. This relationship is characterized by the care that parents provide, and are expected to provide, to their children and is particularistic, referring to the relationship of a parent to a specific child or children. In this volume, we do not presuppose a specific ethical framework, but instead discuss, from different perspectives, the questions, problems and subjects generated by recent research in genetics and neuroscience for the role of parents. For this reason, we chose to focus on the more general term of ‘parental responsibility’ rather than that of ‘parental duties’. Duties are more specific and can be formulated after a normative framework on how to deal with a specific problem or challenge has been determined. By looking at parental responsibilities, we allow for a more broad investigation of what parents should do, or whether they should do anything special at all, in order to live up to the potential demands made visible by certain scientific developments. Another relevant concept in this regard is that of ‘parental obligations’. Following Björnsson and Brülde’s elaboration in this volume, we take obligations to be specific requirements that arise from normative responsibilities. This keeps intact the expression of ‘parental responsibility’ as being the more comprehensive one that is therefore apt to bring together the chapters that are forming this volume.

1.3 This Volume and Its Chapters

Findings in genetics, epigenetics and neuroscience raise important questions about parental responsibility. Should parents endeavour to make their children as *normal* as possible to avoid all problems that they may encounter if they don’t fit in? Is self-control a desirable characteristic, and what does it mean to increase it (see Horstkötter in this volume)? If a neurological condition is embedded in the child’s identity, should we still try to remove or treat it (see Hens in this volume)? How about children whose gender identity does not match stereotypical gender roles (see Giordano in this volume)? Does parental responsibility include preserving a child's fertility (see Cutas in this volume)? How is parental responsibility conceived in non-Western cultures (see Fayemi in this volume)? What do prospective parents themselves think about issues related to the wellbeing of their future children, in the context of prenatal screening (see Hübel in this volume)? The chapters address the various new – and sometimes not so new – questions that arise in the context of genetics and neuroscience on the content and extent of parental responsibility.

In Chap. 2, Gunnar Björnsson and Bengt Brülde provide a theoretical background to the idea of (parental) responsibility. That parents are responsible for the wellbeing of their children is a very common assumption in discussions of what (prospective) parents should do, however these discussions often are unfolded without a clear, explicit, and shared understanding of what responsibility even *is*. Björnsson and Brülde develop these theoretical clarifications in our volume by investigating the relationship between normative responsibilities and corresponding obligations and demands. They argue that normative responsibilities are constituted by normative requirements that the responsible agents *care* appropriately about how well things go in certain regards, and that obligations generally can be seen as straightforward upshots of requirements to care. They also investigate what might be the sources of parental responsibilities: these may include capacities and costs required for taking on the responsibility in question, retrospective and causal responsibility, promises or contracts, and certain social relationships.

In Chap. 3, Anna Bosman criticises the current focus on the Diagnostic and Statistical Manual of Mental Disorders (DSM) and the assumption that medical distinctions between illness and health or between normal and pathological conditions have an objective, *scientific* character. As such, this chapter tackles fundamental issues of how we even define diseases and disorders, which need to be discussed before the scope of parental responsibility can be addressed in practice. Relying on the work of George Canguilhem, she develops a conceptual analysis of disorder. She argues that medicine and psychiatry are not sciences in the same sense as physics and chemistry, because the difference between health and illness, as between normal and abnormal, is always a normative one. It is values, not objective numbers, that determine whether a certain blood level is acceptable or not. Such evaluations cannot focus on individual organisms as such; instead they take into account the relationship between the organism and its environment. Hence a disorder, or as Bosman prefers to term it – a different order – cannot be located in any one individual, instead it is a result of the relationship between the organism and its environment. This understanding about the very meaning of disorder or pathology leads her to some interesting conclusions regarding the responsibilities of parents and other caregivers. They do not need to determine whether someone is different, but whether she suffers. This, however, requires that parents, caretakers and clinicians always reflect upon the norms embedded in current diagnoses and interventions.

In Chap. 4, Elena Syurina and Frans Feron reflect on the current system of child and youth health care (CYHC). They argue that a different theoretical framework is necessary to organize care such that children with developmental problems can be helped in a more timely and efficient fashion. Currently, CYHC support and monitor the development of children from birth to adolescence with a special focus on behavioural and psychosocial issues. Recent findings in both genetics and neuroscience on brain development and on the origin of behavioural disturbances show that problems develop step by step and over considerable periods of time. The authors' main concern is that currently care is provided to children only when they have approached the final and most serious stage of full-blown disorders. However, given that children gradually 'grow into deficit', and given that remission can be achieved more easily during preclinical phases, this approach should be fundamentally changed. CYHC should no longer focus on full-fledged mental health diagnoses, but should be involved already in early preclinical phases, provide early preventive interventions and safeguard access to care for all children who are burdened with difficulties in their psycho-social development.

In Chap. 5, Dorothee Horstkötter investigates the meaning of the concept of self-control, the relevance of childhood self-control for wellbeing and any repercussions these might have on the responsibilities of parents to raise self-controlled children. As she shows in a brief overview of up-to-date research in social psychology, neuroscience, and analytic philosophy, self-control has mainly been linked to willpower and taken to refer to the successful overriding of any inadequate spontaneous responses for the sake of desirable yet distant goals. A critical analysis of current approaches, however, suggests that what has been investigated is 'controlled' behaviour, while the prefix 'self' is hardly given explicit attention. Horstkötter develops a comprehensive understanding of the term that does justice to both aspects. This in turn gives rise to two different sets of educational goals that have separate implications of what it even means to raise self-controlled children. Raising self-controlled children can entail, firstly, to teach them psychological or brain-training strategies to overcome temptation. Secondly, it can imply that parents should support children to develop a self that sets its own goals, reflects on these goals, and considers them as reasons for action. In this sense, while being informative, current neuroscience and social psychology miss out on their aim to identify what is required to raise self-controlled children, because they cannot determine the value children put on any distant goals or spontaneous desires.

Sometimes no established medical treatment can help relieve children's suffering. Farah Focquaert discusses in Chap. 6 the case of paediatric deep brain stimulation (DBS). DBS involves brain surgery and direct stimulation of the brain via electrodes. In the case of Parkinson's disease and essential tremor, this treatment has proved effective in adults. In children, DBS has been used most commonly for dystonia, yet at present it is considered investigational treatment for all paediatric conditions. Paediatric DBS hence is applied only in the framework of therapeutic medical research. Focquaert addresses the ethics of paediatric decision-making and participation in this context. She focuses on two ethically salient issues. First, typically, it is parents who make decisions on behalf of their children and who give, or do not give, their informed consent for treatment. Focquaert, however, argues that shared-decision making that involves the child patient, the parents and the medical team provides the strongest safeguards for the child's best interest. Second, it has been frequently argued that one should first have confirmed successful treatment outcomes in adults before applying the same measures to children. Under certain conditions, however, this rationale should not be followed and instead investigational paediatric DBS might be justified even though no evidence from adults is available.

In Chap. 7, Kristien Hens investigates how epigenetics complicates current discussions on the responsibility of the pregnant woman towards her future child. Epigenetics is a discipline that aims to understand how environmental factors influence organisms on a molecular level and identify how these factors can affect the expression of genes. Epigenetic influences may be heritable and reversible, challenging current assumptions about responsibility in the ethics of genetics. In neurology it is believed that epigenetics partly explains the development of neurological conditions and plays an important role in synaptic plasticity. As many epigenetic changes happen in utero, maternal behaviour may affect brain development. After first discussing new questions raised by epigenetics, Hens then uses the examples of autism and high intelligence (“giftedness”), to investigate the distinction between prevention and enhancement. She describes how some autistic people consider autism a difference rather than a disability, which should be accommodated for rather than cured. Moreover, high intelligence, which is often used as an example of a desirable trait, can lead to social and educational challenges as well. The fact that neurological difference may be considered an identity rather than an affliction is relevant to the discussion about maternal responsibility and epigenetics. If neurodifference is an identity with a value on its own then such responsibility would not entail trying to prevent or cure it.

In Chap. 8, Wybo Dondorp and Guido de Wert discuss the case of pregnant addicted women and the responsibilities that they may have towards their future children. They are particularly concerned about cases in which pregnant women are unwilling or unable to stop their drug use and thereby directly endanger the health and wellbeing of the child. While prenatal child protection is a morally important good, they argue, it is not enough to justify pressure and coercion against pregnant women. Given that any strong pressure (such as requests for legal supervision) and coercion (such as forced hospitalization of pregnant women to avert danger from the child) interfere with women’s rights to self-determination, further criteria must be met. In addition, the harm to be prevented must be plausible, and the measures imposed must fulfil criteria of effectiveness, proportionality and subsidiarity.

In Chap. 9, Simona Giordano reviews the current discussion on gender issues and writes about parental and social responsibilities for children’s gender identity development. She presents recent research on sex and gender identity formation and shows that at least some gender differences are not socially constructed and are expressed already before birth. Moreover, at least in some cases gender identification is congruent with sex differences that are not as immediately evident or testable as are genitals or sex chromosomes. Hence, Giordano argues, although biology may play a role in determining which gender a child identifies with, there is no fixed set of biological markers that can allow us to determine whether an individual is a female or a male. The distinction between sex and gender becomes more complex, as even the biological concept of sex has many different gradations. Moreover, the gender a person identifies with is not always stable across her lifespan. Giordano proposes that sex and gender are treated as broad approximations along a rich spectrum of possibilities. Parents as well as society in general have a responsibility to avoid gender stereotypes and not to insist on binary distinctions.

In Chap. 10, Peter Herissone-Kelly argues that prospective parents are not bound in their reproductive decision-making by the principle of procreative beneficence (PPB). According to the PPB, reproducers have an obligation to choose the embryo that is most likely to become the child that will lead the best life. Herissone-Kelly argues that the considerations that constitute the PPB reflect an *external perspective*, one that considers which future child, from possible children, is likely to have the best life. Such a perspective may be appropriate for policy makers. The appropriate perspective for prospective parents is, however, an *internal* one: parents consider what it is like for their specific future child to live a certain life. The sorts of considerations that underlie the principle of procreative beneficence do not constitute sufficient reasons to imply an obligation for prospective parents. Hence, there can be no requirement for prospective parents to be moved by those considerations.

Francisco Güell takes another route in Chap. 11 to challenging the PPB. Instead of examining, like Herissone-Kelly, whether parents are bound by the principle, he depicts a complex picture of the array of risks and black boxes that are actualised by the use of IVF, which is a necessary step to put the PPB into practice. On that basis, he casts doubts onto whether by acting on the PPB we really are *avoiding* rather than *creating* risks. Not talking about the risks involved in IVF, while emphasising risks that parents could actualise in their daily life (by smoking, alcohol intake or stress), creates an arbitrary distinction between the two sources of risk. In the current situation, the latter of these situations is presented as heavily loaded with meaning from a responsibility perspective, while the former is seen as responsibility free. Güell makes a case for equipping prospective parents with adequate information to enable them to make reproductive choices – and this information must include an honest evaluation of the risks involved in making recourse to IVF, particularly if that would not be for reasons of infertility but for the aim of procreative 'benefit'.

In Chap. 12, Daniela Cutas discusses the question of whether parents have a responsibility to take active steps to *rescue* their children's fertility. Starting with the case of treatments with a high risk of rendering children infertile, she examines the case for fertility preservation, as well as some of its possible implications: do only children who run an immediate risk of losing their fertility have a right that their parents (or someone else) rescue their fertility, or do others as well, and on what grounds? If (some) children have a right to fertility preservation, why should it be up to the parents to determine whether this right should be exercised? Can we draw a distinction between fair and unfair, deserved and undeserved capacity to reproduce – and use it in practice? By discussing these questions and more, Cutas tests intuitions and arguments and unfolds some of the complexities of the idea that parents have responsibilities regarding their children's reproductive capacities.

Illustrating the tension between deeply held beliefs and understandings of genetic conditions and the explanations and possibilities offered by modern medicine and genetics, Ademola Fayemi explores in Chap. 13 the example of sickle cell anaemia (SCA) in Yoruba culture in Nigeria. In this culture, responsibility for children is shared between members of the extended families in which children are born – and not limited to the children's parents (according to a Yoruba proverb, "children are biologically born by two eyes (…) but collectively nurtured by more than a thousand eyes"). This helps lift some of the burdens of coping with difficult situations in children's lives, but at the same time sustains age-old explanations and treatments that discourage uptake of information and support from modern medicine and technology. This case is a powerful and telling example of the need to find the best solutions for children, their parents, their families, and ultimately entire communities, in a way that profits at the same time from the goods in a culture and the goods in science and technology.

As is by now apparent from the more theoretical chapters in this volume, the issue of whether prospective parents have a duty to select the healthiest possible children is controversial and much discussed in recent years. In Chap. 14*,* Sylvia Hübel and colleagues present an empirical study in which they gained insight into views and attitudes regarding prenatal diagnosis and parental autonomy among health care professionals and parents who had recently undergone prenatal testing. They found that many (prospective) parents reject the idea of parental responsibility as having to select the healthiest possible children. Instead, parents have internalised the responsibility to respect lifestyle recommendations during pregnancy and to give the best possible care after birth. Hübel and colleagues also found that health care professionals thought that the main task of counselling in the case of prenatal testing was to provide prospective parents with help in making their own informed choices. However, at the same time, health care professionals also reported ethical dilemmas, such as what to do if prospective parents wanted testing or termination for minor anomalies, or if they did not want testing even though they had a high risk of transmitting a severe disease. In sum, professionals subscribe to the ideal of non-directive counselling, although parents as well as professionals themselves doubt the feasibility and desirability of adhering to this ideal in all cases.

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